TRENDS IN DOCUMENTED AUTISM SPECTRUM DISORDER CO-OCCURRING CONDITIONS AND SPECIAL EDUCATION EXCEPTIONALITY IN CHILDREN WITH AUTISM SPECTRUM DISORDER IDENTIFIED BY THE AUTISM AND DEVELOPMENTAL DISABILITIES MONITORING NETWORK, 2002, 2006, AND 2008

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Abstract

Autism spectrum disorder (ASD), an impairment of social communication and interaction, affects 1 in 68 eight-year-olds. The Autism and Developmental Monitoring Network (ADDM) found prevalence increased 78% from 2002 to 2008. Part one assesses documented ASD co-occurring conditions (DACCs) for eight-year-olds with ASD identified by ADDM in 2002, 2006, and 2008. Children were included if they were identified by an ADDM site that abstracted medical records and collected IQ data on greater than 85% of children, and the child lived in an area that participated in all three surveillance years. Negative binomial regression and rare events logistic regression were used to test for trends in count and by categorized and individual DACCs. The same approach was used examine the multiplicative effects of prior documentation of ASD on the child's records and intellectual disability (ID). Number of DACCs significantly increased for children with ID and all children with prior documentation of ASD. Increasing DACCs were mainly specific developmental delays (SDD); this may be a result of increased early developmental screening. SDDs that increased differed within the subgroups. In part two, trends in special education exceptionality from 2002, 2006, and 2008 in the ADDM network were assessed. Special education exceptionality is a US government mandated classification system for children who meet criteria for special education services. Children were included if they had exceptionality, identified as having ASD by a site in the ADDM network, had abstracted school records, and lived in the surveillance area for all three surveillance years, Rare events logistic regressions were conducted to test trend. Trends in exceptionality type stratified by sex and race/ethnicity were assessed to evaluate possible disparities. Results were compared to Individuals with

Disabilities in Education Act (IDEA) data. Autism exceptionality remained constant for the total sample and in all subgroups but females. ID classification significantly decreased for both sexes and white and black children and differed significantly among sexes and race/ethnicity. Developmental disability exceptionality increased for all subgroups but did not differ and may be partially attributable to the increase in early developmental screening. Comparing to national data, exceptionality classification for children with ASD is not increasing with increased ASD prevalence. Better understanding classification patterns will help better service allocation for children with ASD.

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Preface

I would like to thank the ADDM team (Drs. Jon Biao, Cathy Rice, Laura Schieve, Lisa Wiggins, Kim Van Naarden Braun, Daisy Christensen, Amanda Bakian, Maureen Durkin, Russell Kirby, Steve Rosenberg, Julie Daniels, Julie Preskitt) for support and guidance on this thesis. Dr. Gayane Yenokyan was a great help in solidifying the statistical methods for this thesis. Dr. William Eaton was courteous enough to be a reader on this project. Lastly, Dr. Li-Ching Lee was more than could be asked for as an advisor and mentor. I thank her for the constant support and opportunity to work on this project.

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Introduction

Autism spectrum disorder (ASD) is an impairment of social communication and social interaction marked by repeated and restricted behaviors and interests (American Psychiatric Association, 2013). The most recent prevalence estimate conducted by the Autism and Developmental Disabilities Monitoring network (ADDM), an active surveillance system in the US, has found ASD to be present in 1 in 68 eight-year-olds (Autism and Developmental Disabilities Monitoring Network, 2014). Both the ADDM network and the National Health Interview Survey (NHIS) have found a substantial increase in prevalence of ASD from 2002 to 2008 (Autism and Developmental Disabilities Monitoring Network, 2012; Boyle et al., 2011). Prevalence of ASD in eight-year-old children in the ADDM network rose from .6% in 2002 to 1.14% in 2008 (Autism and Developmental Disabilities Monitoring Network, 2012) and prevalence of ASD in children aged 3-17 in the NHIS increased from .35% in the 2000-2002 surveillance period to .74% in the 2006-2008 surveillance period (Boyle et al., 2011).

With a significant increase in prevalence, it is worthwhile to assess trends in factors associated with ASD diagnosis and opportunities for services. This paper will address two such factors: documented ASD co-occurring conditions (DACCs) and special education exceptionality. Evaluating trends in these features may enlighten diagnostic patterns in children born in 1994, 1998, and 2000 and provide information on possible relationships between these features and the rise in prevalence of ASD.

1. Trends in documented ASD co-occurring conditions in children with ASD identified by the Autism and Developmental Disabilities Monitoring Network, 2002-2008

1.1 Background

Co-occurring conditions are prevalent in children with ASD as 83% of eight-year-old children with ASD in the 2002 ADDM surveillance year had a co-occurrence of one or more non-ASD conditions (Levy et al., 2010). This high prevalence of co-occurring conditions for children with ASD has been seen repeatedly in the literature (Baird et al., 2008; Close, Lee, Kaufmann, & Zimmerman, 2012; Mattila et al., 2010; Newschaffer et al., 2007; Schendel, Autry, Wines, & Moore, 2009; Simonoff et al., 2008). Common co-occurring conditions for children with ASD include language disorders, specific developmental delays (SDD), attention deficit hyperactivity disorder (ADHD), intellectual disability (ID), sensory integration disorder, observational defiance disorder, anxiety disorders, and epilepsy (Levy et al., 2010; Simonoff et al., 2008). Documented ASD co-occurring conditions (DACCs) are defined as conditions present in children with ASD that have been identified and noted by a healthcare professional. DACCs are important when studying ASD because they may help us better understand the extent to which they impact ASD diagnosis determination (Rosenberg, Daniels, Law, Law, & Kaufmann, 2009).

As ASD has increased, other neurodevelopmental conditions amongst children have remained constant or increased at a lower rate than ASD. For example, the NHIS found no significant change in the prevalence of cerebral palsy (.15% in 2000-2002 to .18% in 2006-2008), hearing loss (.44% to .38%), and ID (.73% to .67%) (Boyle et al.,

2011). There was a significant increasing trend in ADHD (6.71% to 7.57%) and SDD (3.28% to 4.24%) but those increases were not as large as the increase in prevalence of ASD (Boyle et al., 2011). These results may suggest that not all neurodevelopmental diagnoses are increasing in prevalence, which may indicate that the increase in ASD prevalence is not reflective of an increase in diagnoses for all neurodevelopmental disorders. It has been hypothesized that the increase in ASD may be due in part to a classification change of children from ID to ASD (Grether, Rosen, Smith, & Croen, 2009), but the results from the NHIS may imply that the rise in ASD prevalence is not coming solely from a switch from an ID diagnosis to an ASD diagnosis. Additionally, there may be an association between the increase in certain neurodevelopmental disorders (ASD, SDD, and ADHD) and the increase in early developmental screening (Arunyanart et al., 2012; Radecki, Sand-Loud, O'Connor, Sharp, & Olson, 2011).

DACCs may be associated with receipt of ASD diagnosis. Disruptive behaviors and other associated features of ASD may make it more difficult for a clinician to make an appropriate diagnosis. Matson and colleagues (2012) use the example of a child with challenging behaviors throwing a tantrum during an observation period, hampering the clinician's ability to evaluate ASD. In the past, a clinician may have been more likely to diagnose a person with ID rather than the appropriate diagnosis of ASD because a lack of awareness and or knowledge about ASD (Rosenberg et al., 2009).

ID has been shown to be associated with certain DACCs; studies have shown presence of co-occurring ID in ASD is associated with co-occurring epilepsy (Amiet et al., 2008), ADHD (Gadow, Devincent, Pomeroy, & Azizian, 2005), and mood disorder (Gadow et al., 2005). Overall, the trend of co-occurring ID in people with ASD has

decreased. In a study conducted by Rosenberg and colleagues (2009), approximately 50% of ASD cases identified from 1994-2001 by the Interactive Autism Network had co-occurring ID while only 20% had ID from 2002-2007. In a review of ASD epidemiology, Fombonne (2005) found the prevalence of co-occurring ID to be near 70% after averaging 19 studies from 1966 to 2001, whereas the robust 2010 ADDM surveillance report found ID to be prevalent in 31% of eight-year-olds with ASD (Autism and Developmental Disabilities Monitoring Network, 2014). Identification of children with ASD and typical IQ may be improving and thus, the increase in ASD prevalence could be partially due to the identification of these previously unidentified cases. If this is true, we would expect to see a decrease in DACCs over the three surveillance years, as the additional ASD cases added over time do not have as strong of an association with co-occurring conditions as those children with ASD and co-occurring ID.

The purpose of this study is to describe trends count of DACCs, percent with a DACC in a specified diagnostic category, and percent with a DACC for a specific condition in children with ASD identified by the ADDM network. Multiplicative effects of ID status and previous documentation of ASD diagnosis in child's education or health records will be examined; this will assess the impact of ID and early ASD identification on DACCs and diagnostic practices. We hypothesize that there will be an increase in DACCs over three surveillance years, there will be a rise in the developmental delay category, and SDD subtypes subsumed in that category will increase. Lastly, we hypothesize that DACCs will be more prevalent in children with ID and in children with existing documentation of ASD.

1.2 Methods

ADDM Network data were used for this analysis. The ADDM Network is a multiple source population-based surveillance system of ASD prevalence in eight-year-old children. The network was established by the Centers for Disease Control and Prevention in 2000 (Autism and Developmental Disabilities Monitoring Network, 2014). Over the course of the network, sixteen sites have contributed data (Alabama, Arkansas, Arizona, Colorado, Florida, Georgia, Illinois, Maryland, Missouri, North Carolina, New Jersey, Pennsylvania, South Carolina, Utah, Wisconsin, and West Virginia) (Autism and Developmental Disabilities Monitoring Network, 2014). This study includes sites that participated in study years 2002, 2006, and 2008; 2000 and 2004 were not included due to poor site participation. The sample was limited to ADDM sites that had IQ information for >85% of ASD cases in order to minimize missing data. Additionally, a child had to live within a geographic area surveyed for all three surveillance years, ensuring a common catchment area controlled for changing sample areas between surveillance years. Each site met their local institutional review board requirements.

1.2.a Data collection and ASD case status

Data were systematically collected and abstracted from a variety of educational and health resources. Medical, behavioral, psychiatric, and developmental histories, as well as symptoms, and diagnoses consistent with DSM-IV-TR were collected for each child. Information on the child was linked and a record was created with a unique subject ID number. A research-trained clinician used a highly structured scoring protocol based on the DSM-IV-TR to ascertain ASD case status for each child abstracted using records that were available. In the 2008 study year, inter-rater reliability was established for all sites and maintained on a random sample of greater than 10% of abstracted records:

overall agreement was 90.2% and kappa was .8 (Autism and Developmental Disabilities Monitoring Network, 2012).

1.2.b DACCs

A child was considered to have DACC if there was a clear statement in the child's records by a community professional that the child met criteria for a specific disorder. Any instance of a DACC from birth to time of record abstraction is included. Each DACC was placed into one of four mutually exclusive broader categories based on groupings of co-occurring conditions created by Levy and colleagues (2010). The four categories are a) developmental conditions (ADHD, language disorder, learning disability, SDD general, SDD adaptive, SDD cognitive, SDD motor, SDD social personal, SDD play, non-verbal learning disorder, and sensory integration disorder) b) psychiatric conditions (anxiety disorder, conduct disorder, oppositional defiant disorder, obsessive compulsive disorder, bipolar disorder, depression, emotional disorder, mood disorder, mutism, obsessive compulsive disorders, psychosis, reactive attachment disorder, and schizophrenia) c) neurologic diagnoses (encephalopathy, cerebral palsy, seizures or epilepsy, brain injury, vision impairment, hearing loss, Tourette syndrome) and d) possible causative conditions (tuberous sclerosis, Down Syndrome, Fragile X syndrome). Tables and figures present individual DACCs if they have >10% prevalence in at least one surveillance year.

1.2.c Data Analyses

Analyses were performed using Stata 12.1 (College Station, TX). For each surveillance year, trend in overall count of DACCs were calculated using negative binomial regression accounting for clustering by study site. This technique was used

because count of DACCs did not meet the proportional odds assumption. Site specific clustering was accounted for due to possible effects of policy and practices in the different sites. The 2002 surveillance year was used as a reference group and t-tests were conducted to compare change from 2002 to 2006 to change from 2002 to 2008 (both changes were calculated from the regression model); if the difference was significant at a $P < 0.05$ level overall trend was deemed significant. This P value is presented in the tables. Rare event logistic regression was used when assessing categorized and individual DACCs; this method was ideal because of its capability to handle conditions with low frequency (G. King & Zeng, 2001). Again, due to differing study staff and state reporting requirements, clustering at the study site level was accounted for in the regression model. The same t test procedure used for count data was used to determined trend. Tests were repeated after stratifying by whether there was a prior documentation of ASD diagnosis in the child's records and after stratifying by ID status. If a child had a documentation of diagnosis of ASD, autistic disorder, Asperger's syndrome, pervasive developmental disorder, an ICD code of 299.0 or 299.8, or a noted age at first ASD diagnosis, then the child was denoted as having a 'previously documented ASD diagnosis'. If not, they were denoted as 'no previous documented ASD diagnosis.' ID status was categorized as 'has an intellectual disability', 'does not have an intellectual disability', or 'intellectual disability status missing.' ID was defined as IQ $\leq$70 based on DSM 5 criteria (American Psychiatric Association, 2013). These variables were derived from the most recent IQ test taken or a diagnosis of ID in the child's records. If a child did not have documented ID status, they were not included in the analyses stratified by ID; this was determined after deeming ID to be missing completely at random. No significant relationship was seen

between missing ID status and sex, race, previous documentation of ASD. There was a significant association between missing ID status and surveillance site; however, the association was similar to the association between site and study year for the total sample. Tables and tests for missing data are presented in the appendix. The lack of meaningful association allows us to justify our belief that ID status is missing completely at random and children with missing ID can be dropped from the stratified analyses by ID without inducing bias. When stratified by ID status, ID was not included as a DACC as it would result in a double counting of ID. Multiplicative effects were tested if trends in both stratified subgroups (with and without ID or with and without prior documentation) were significant. A covariate that multiplied ID status by study year or prior documentation by study year were created and added to the total sample regression model to determine whether there were significant differences between DACC in subgroups.

1.3 Results

Table 1.1 presents demographic characteristics and average age of first ASD diagnosis for 4,051 children who met selection criteria. Demographic differences between the three surveillance years include increases in children with Hispanic ethnicity (9.1% in 2002 to 12.9% in 2008) and previous documentation of ASD on a child's records (59.1% to 64.9%). There were decreases in white, non-Hispanic ethnicity (56.4% to 49.3%), documentation of ID on a child's records (43.8% to 36.4%) and average age at first diagnosis of ASD (62.9 months to 56.4 months).

Mean numbers of DACCs are provided in table 1.2 for the total sample as well as for subgroups. DACCs increased overall (1.83 conditions per child in 2002 to 2.09 in 2008) and in each subgroup; however, only children with previous documentation of

ASD on their records (9.3% increase from 2002-2008, P< .001) and children with ID (23.8% increase, P= .0027) had significant increases. Figure 1.1 illustrates the distribution of DACCs in the three surveillance years.

Frequencies and regression results are provided for categorized and individual DACCs in table 1.3 for the total sample. The only significant change in a DACC category was for possible causative medical conditions but this may be due to small sample size. For individual DACCs, SDD adaptive (37.3% increase, P= .02), SDD motor (23.7%, P= .01), SD personal (29%, P< .001), and learning disorder (9.6%, P< .001) showed an increasing trend. All other DACCs did not reach significance.

Table 1.4 presents categorized and individual DACCs for children with ASD stratified by previous documentation of an ASD diagnosis. Individual DACCs are presented if there is >10% prevalence for any one surveillance year. Those with a previous documentation of ASD had an increasing trend in developmental (16.1% increase, P< .001) and neurological (14.3% increase, P= .03) DACC categories; those without had a decreasing trend in the psychiatric category (24.3% decrease, P< .001). For individual DACCs, both groups had a significant increase in learning disorder (30.3 and 9.6% respectively, P< .001 for both) and change differed between the two groups (P < .001). For children with a previous documentation of ASD, ADHD (13.3% increase, P< .001), SDD adaptive (32.4% increase, P< .001), and language disorder (9.4% increase, P< .001) increased and SDD personal (18.9% decrease, P< .001) decreased. Children without previous documentation of ASD had an increasing trend in SDD cognitive (53.2% increase, P= .014), SDD language (27.3% increase, P< .001), SDD motor (32.9% increase, P= .05), and SDD personal (68.9% increase, P< .001).

Table 1. 1 Frequency and percentage of demographic variables among ASD cases identified by the Autism and Developmental Disabilities Monitoring Network, 2002, 2006, and 2008

		2002 N=871	**2006** N=1518 **N (%)**	**2008** N=1662 **N (%)**
Sex		**n (%)**	**n (%)**	**n (%)**
	Male	719 (82.5)	1148 (83.0)	1392 (83.8)
	Female	152 (17.5)	235 (17.0)	270 (16.3)
Race				
	White, non-Hispanic	491 (56.4)	735 (53.1)	819 (49.3)
	Black, non-Hispanic	249 (28.6)	326 (23.6)	459 (27.6)
	Hispanic	79 (9.1)	188 (13.6)	215 (12.9)
	Other / Missing	52 (6.0)	134 (9.7)	169 (4.3)
Site				
	Arizona	259 (29.7)	495 (32.6)	507 (30.5)
	Georgia	337 (38.7)	474 (31.2)	601 (36.2)
	North Carolina	135 (15.5)	353 (23.3)	290 (17.5)
	South Carolina	140 (16.1)	196 (12.9)	264 (15.9)
ID				
	Child has an ID	382 (43.8)	545 (35.9)	605 (36.4)
	Child has no ID	430 (49.4)	54.2 (52.7)	940 (56.6)
	ID status is missing	59 (6.7)	149 (9.8)	117 (7.0)
Previous documentation of ASD in records				
	Yes	515 (59.1)	856 (61.9)	1078 (64.9)
	No	356 (40.9)	527 (38.1)	584 (35.1)
Age at first ASD diagnosis in months (% missing)				
		62.9 (45)	56.1 (46)	56.4 (38)

Table 1. 2 Mean number of DACCs and trend tests from 2002, 2006, and 2008 in the ADDM Network

Sample subtype	2002	2006	2008	P Value for trend*	% Change 2002-2008
Total	1.83	1.81	2.09	.14	14.2
If previously documented ASD	1.94	2.01	2.12	**< .001**	9.3
If no previously documented ASD	1.68	1.92	2.06	.23	22.6
With ID	1.81	2.12	2.24	**.0027**	23.8
Without ID	1.70	1.76	1.90	.22	11.8

*P value for all tables tests whether the change from 2002 to 2006 is significantly different from the change between 2002 and 2008

Figure 1. 1 Distribution of DACCs in the ADDM network 2002, 2006, and 2008

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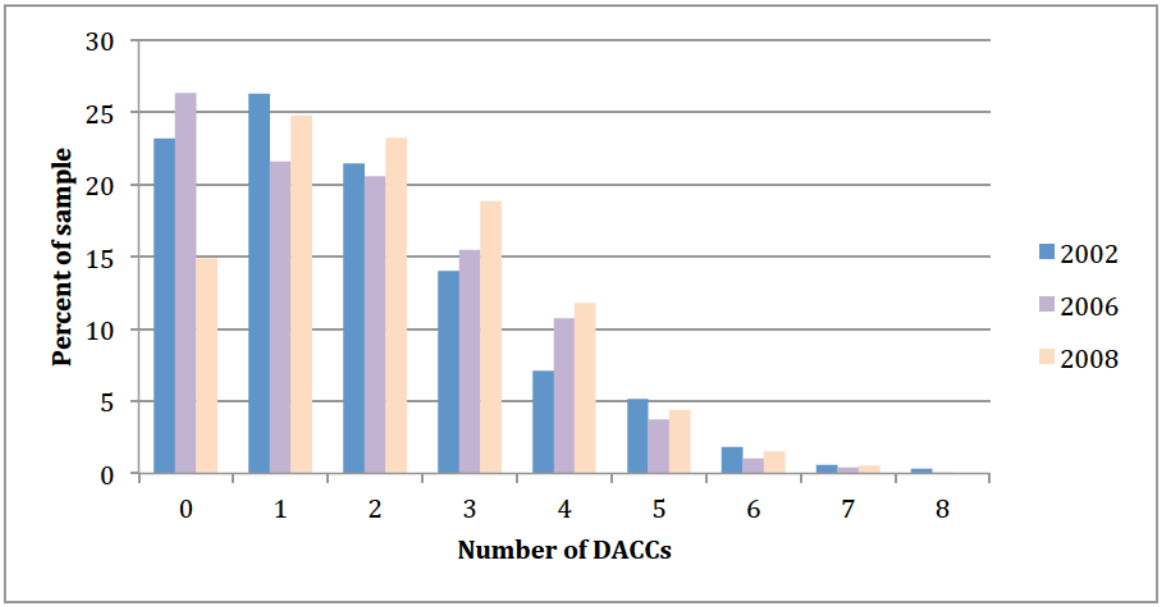


Table 1. 3 Trends in DACCs for all ADDM identified ASD cases, 2002, 2006, and 2008

Condition	2002 N= 871	2006 N= 1516	2008 N=1662	P Value for trend	% Change 2002-2008
Categorized DACC's	**n (%)**	**n (%)**	**n (%)**		
Developmental	488 (56.0)	861 (56.7)	1088 (65.4)	.17	16.8
Psychiatric	56 (7.7)	73 (5.4)	95 (5.7)	.34	-26.0
Neurological	29 (1.9)	63 (4.2)	66 (4.0)	.67	110.5
Possible Causative Medical	5 (0.57)	2 (0.13)	6 (0.36)	**< .001**	-36.8
Individual DACC's					
ADHD	87 (10.0)	124 (8.1)	171 (10.3)	.16	3.0
SDD Adaptive	178 (20.4)	324 (21.3)	466 (28.0)	**.02**	37.3
SDD Cognitive	163 (18.7)	252 (16.6)	363 (21.8)	.07	16.6
SDD General	160 (18.4)	265 (17.5)	293 (17.6)	.95	-4.3
SDD Language	211 (25.4)	399 (26.3)	490 (29.5)	.28	16.1
SDD Motor	154 (17.7)	311 (20.5)	364(21.9)	**.01**	23.7
SDD Personal	153 (17.6)	264 (17.4)	377 (22.7)	**< .001**	29.0
ID	111 (12.7)	181 (11.9)	193 (11.6)	.87	-8.7
Language Disorder	179 (20.6)	311 (20.5)	385 (23.2)	.26	12.6
Learning Disorder	45 (5.2)	64 (4.2)	95 (5.7)	**< .001**	9.6

***** All categories and diagnoses are not exclusive, ADHD= attention deficit and hyperactivity disorder, SDD= significant developmental delay, ID= intellectual disability

Table 1. 4 Trends in DACCs among children with ASD identified by ADDM stratified by prior indication of ASD, 2002, 2006, and 2008

	Documentation of previous ASD diagnosis					No documentation of previous ASD diagnosis				
Condition	**2002** N=515	**2006** N=856	**2008** N=1078	**P Value for trend**	**% Change 2002-2008**	**2002** N= 356	**2006** N= 527	**2008** N=584	**P Value for trend**	**% Change 2002-2008**
Categorized DACC	**n (%)**	**n (%)**	**n (%)**			**n (%)**	**n (%)**	**n (%)**		
Developmental	297 (57.7)	539 (63.0)	722 (67.0)	**< .001**	16.1	191 (53.7)	322 (61.1)	366 (62.7)	.30	16.8
Psychiatric	31 (6.0)	44 (5.1)	64 (5.9)	.77	-1.7	25 (7.0)	29 (5.5)	31 (5.3)	**< .001**	-24.3
Neurological	18 (3.5)	48 (5.6)	43 (4.0)	**.03**	14.3	11 (3.1)	15 (2.9)	23 (3.9)	.68	25.8
Possible Causative Medical	1 (.19)	1 (.12)	3 (.28)	.89	47.4	4 (1.12)	1 (.19)	3 (.51)	.087	-54.5
Individual DACCs										
ADHD	54 (10.5)	75 (8.8)	128 (11.9)	**< .001**	13.3	33 (9.3)	49 (9.3)	43 (7.4)	.13	-20.4
SDD Adaptive	113 (21.9)	211(24.7)	313 (29.0)	**< .001**	32.4	65 (18.3)	133 (21.4)	153 (26.2)	.45	43.2
SDD Cognitive	109 (21.2)	157 (18.3)	227 (21.1)	.72	-0.5	54 (15.2)	95(18.0)	136 (23.3)	**.014**	53.2
SDD General	104 (20.2)	184 (21.5)	200 (18.6)	.053	-7.9	56(15.7)	81 (15.4)	93 (15.9)	.98	1.3
SDD Language	131 (25.4)	244 (28.5)	302(28.0)	.83	10.2	90 (25.3)	155 (29.4)	188 (32.2)	**< .001**	27.3
SDD Motor	99 (19.2)	200 (23.4)	244 (22.6)	.83	17.7	55 (15.5)	111 (21.1)	120 (20.6)	**.05**	32.9
SDD Personal	105 (20.4)	159 (18.6)	244 (22.6)	**< .001**	-18.9	48 (13.5)	105 (19.9)	133 (22.8)	**< .001**	68.9
ID	68 (13.2)	117 (13.7)	115 (10.7)	.39	-13.1	43 (12.1)	64 (12.1)	78 (13.4)	.56	10.7
Language Disorder	110 (21.4)	186 (21.7)	261 (24.2)	**< .001**	9.6	69 (19.4)	125 (23.7)	124 (21.2)	.089	9.3
Learning Disorder*	17 (3.3)	25 (2.9)	46 (4.3)	**< .001**	30.3	45 (5.2)	64 (4.2)	95 (5.7)	**< .001**	9.6

Table 1.5 presents data for categorized and individual DACCs for all children with ASD stratified by ID status. Those with ID had an increasing trend in the developmental category (32.8% increase, P< .001) while both groups had a decreasing trend in the psychiatric category (42.1% decrease P= .0015 for children with ID, 8.6% decrease P< .001 for those without); trends did not differ between subgroups (P= .173). For individual DACCs, both children with and without ID had increasing trends for SDD personal (21.1% increase P< .001 for children with ID, 33.3% increase P= .018 for children without) which did not differ between groups (P= .958). Children with ID had an increasing trend in ADHD (11.8% increase, P= .011), SDD adaptive (50.6% increase, P< .001), SDD cognitive (31.8% increase, P< .001), and language disorder (41.6% increase, P= .026). Children without ID had an increasing trend in SDD motor (18.4% increase, P= .037) and a decreasing trend in language disorder (7.7% decrease, P= .016). The trends in language disorder significantly differed between the two groups (P < .001).

1.4 Discussion

These findings support prior literature and add to our knowledge about DACCs in children with ASD. DACCs, as seen in the ADDM network, are highly prevalent and have become significantly more frequent over time in subgroups with co-occurring ID and previous documentation of ASD on health records. In the entire sample, SDD adaptive, SDD motor, SDD personal, and learning disorders had significant increasing trends. Children without prior documentation of ASD have more significant increases in SDD domains (cognitive, language, motor, personal) as compared to children with prior documentation of ASD. In children with ASD and co-occurring ID, the developmental category had a strongly significant increasing trend that was not seen in children without

ID. Additionally, children with and without ID differed in which SDD groups had increasing trends.

By stratifying by previous documentation of ASD on a child's records and ID status, we can assess how diagnostic patterns may have changed for certain subgroups. The increasing trend in count of DACCs for children with prior documentation of ASD on records and for children with co-occurring ID may be due to the greater likelihood of a more pronounced ASD phenotype leading to parental concern and increased doctors visits. As awareness of ASD and developmental screening of infants and young children increase (Boyle et al., 2011; Radecki et al., 2011), children with more severe presentation (including presence of ID) are more likely to have an ASD diagnosis and receive it an earlier age (Close et al., 2012; Mandell, Novak, & Zubritsky, 2005). In this case, it is possible that the greater amount of time that a child receives services and care for ASD, the more opportunities to receive DACCs.

The consistent increasing trends in certain SDD categories may be in part due to an increase in developmental screening. In a 2002 US national random sample of pediatricians, 23% were found to always or almost always conduct standardized screenings for early developmental delays; by 2009, 48% of responded that they always or almost always conduct these screenings (Radecki et al., 2011). In the NHIS study of children 3-17 years, the overall prevalence of a documented SDD increased 17% from 1998-2008 (Boyle et al., 2011) so it is possible that we would see the increase in SDD in children with ASD, especially since many times a diagnosis of an SDD precedes a diagnosis of ASD.

Table 1. 5 Trends in DACCs in children with ASD identified by the ADDM Network stratified by ID status, 2002, 2006, and 2008

	Intellectual Disability					No Intellectual Disability				
Condition	**2002** N=382	**2006** N=545	**2008** N=605	**P Value for trend**	**% Change 2002-2008**	**2002** N=356	**2006** N=527	**2008** N=940	**P Value for trend**	**% Change 2002-2008**
Categorized DACC	**n (%)**	**n (%)**	**n (%)**			**n (%)**	**n (%)**	**n (%)**		
Developmental	159 (54.6)	245 (62.2)	324 (72.5)	**< .001**	32.8	219 (52.9)	408 (51.9)	541 (59.6)	.33	12.6
Psychiatric	11 (3.8)	12 (3.3)	10 (2.2)	**.0015**	-42.1	40 (9.3)	56 (6.8)	80 (8.5)	**< .001**	-8.6
Neurological	16 (5.5)	25 (6.9)	22 (4.9)	.77	-10.9	7 (1.63)	26 (3.16)	27 (2.87)	.57	76.1
Possible Causative Medical	2 (0.68)	1 (0.27)	1 (0.22)	-	-67.6	1 (0.23)	0 (0.0)	3 (0.32)	-	39.1
Individual DACC										
ADHD	20 (6.8)	18 (4.9)	34 (7.6)	**.011**	11.8	52 (12.6)	87 (11.9)	112 (12.3)	.62	-2.4
SDD Adaptive	68 (23.3)	102 (28.0)	157 (35.1)	**< .001**	50.6	73 (17.7)	157 (21.4)	226 (24.9)	.14	40.7
SDD Cognitive	81 (27.7)	99 (27.2)	163 (36.5)	**< .001**	31.8	48 (11.6)	104 (14.2)	154 (17.0)	076	46.5
SDD General	70 (24.0)	111 (30.5)	107 (23.9)	.71	-0.4	57 (13.8)	89 (12.1)	109 (12.0)	.81	-13.0
SDD Language	74 (25.3)	128 (35.2)	146 (32.7)	.092	29.2	111 (26.9)	188 (25.7)	250 (26.8)	.52	-0.4
SDD Motor	48 (16.4)	90 (24.7)	114 (25.5)	.28	55.5	72 (17.4)	152 (20.7)	187 (20.6)	**.037**	18.4
SDD Personal	54 (18.5)	82 (22.5)	100 (22.4)	**<. 001**	21.1	73 (17.7)	144 (19.7)	214 (23.6)	**.018**	33.3
Language Disorder *	54 (18.5)	86 (23.6)	117 (26.2)	**.026**	41.6	97 (23.5)	153 (20.9)	197 (21.7)	**.016**	-7.7
Learning Disorder	7 (2.4)	4 (1.1)	9 (2.0)	.12	-16.7	37 (9.0)	56 (7.6)	79 (8.7)	30	-3.3

(Council on Children With Disabilities Section on Developmental Behavioral Pediatrics Bright Futures Steering Committee Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006). Nonetheless, due to the unknown dates when the DACCs were received, we cannot determine for certain whether the increase in SDD diagnoses seen preceded the rise in early developmental screenings.

Limitations are important to consider. Only DACCs from school and medical records were assessed; thus, information on conditions that were not documented is unknown. We additionally did not always know the type of evaluation or the standardized criteria used when diagnosing the child and had to rely on the judgment of the clinician conducting the examination. Furthermore, due to the lack of information about the age at which the child receives the co-occurring condition, we cannot determine whether the DACC preceded the ASD diagnosis. Age when the co-occurring condition was noted would also allow us to assess trends by calendar year rather than by birth cohort. In relation to age, many DACCs (such as schizophrenia and some mood disorders) typically present at later ages. This study only assessed children aged eight and we cannot draw any conclusions about trends in the later developing DACCs. By stratifying by previously indicated ASD diagnosis, we hoped to address some of the temporality issues. We attempted to account for geographic clustering by adjusting for site but that does not account for differences at smaller geographical levels. Due to the de-identified nature of the records, we could not control for diagnostic factors at a city or community level. Lastly, we were unable to assess the interaction of previous documentation of ASD and ID status together due to limited sample size.

ADDM network data is limited by its use of record review. These methods introduce response bias, attrition, and high cost; therefore, misclassification and diagnostic substitution may be introduced. Additionally, this study only used data from four sites and is not a US representative sample. Results may not be generalizable to the entire US population.

A major strength of this study is its use of multiple time points to address changes in DACCs. The use of a consistent sampling area and rigorous methods allows us to accurately assess these changes with little worry about confounding due to changes in geographic area of the sample. Stratifying by previous documentation of ASD allows us to determine the relationship between the identification of ASD and DACCs and provides some insight into diagnostic practices. By selecting sites with high IQ collection, we were able to stratify and assess the impact of ID on DACCs. This is one of the first studies to compare trends in DACCs in children with ASD with and without ID.

1.5 Conclusions

Prevalence of DACCs in children with ASD identified by ADDM remains high and has significantly increased in eight-year-old children with a previous documentation of ASD and co-occurring ID. Most common increasing DACCs were SDDs and this may be partially a result of increased early developmental screening during infancy in the later cohorts. SDDs that increased were different between both children with and without prior documentation of ASD and children with and without ID. These data highlight diagnostic tendencies of clinicians from 1996-2008 and may partially illustrate the effect of severity of ASD presentation, increased developmental screening, and increased awareness of ASD.

2. Trends in special education exceptionality in children identified with ASD by the Autism and Developmental Disability Monitoring Network, 2002, 2006, and 2008

2.1 Background

In 1991, the US Federal Government included autism as a special education exceptionality in the Individuals with Disabilities Education Act (IDEA) (108th United States Congress, 2004). This act mandates individual education programs (IEP) for children and young adults aged 3-21 who fit into one of 14 distinct special education exceptionalities (108th United States Congress, 2004). These exceptionalities are autism, deaf-blindness, deafness, developmental delay (DD), emotional disturbance, hearing impairment, intellectual disability (ID), multiple disability, orthopedic impairment, other health impairment, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments (108th United States Congress, 2004). Specific learning disabilities are defined as disorders in one or more psychological processes that involve the understanding or usage of language (108th United States Congress, 2004). Speech or language impairments are communication disorders that adversely affect a child and include stuttering, impaired articulation, and language or voice impairment (108th United States Congress, 2004). By assessing trends in special education exceptionality for children with autism spectrum disorder (ASD) we may be able to assess possible influences of change in screening practices and trends in diagnostic substitution, and / or diagnostic accretion.

It has been hypothesized that the increase in ASD prevalence may be due in part to a raised awareness of ASD, changes in diagnostic criteria, and improved surveillance

systems (Fombonne, 2005). Some prior research, such as Croen and colleagues (2002) analysis of California birth cohorts and Coo and colleagues (2008) assessment of special education classification in British Columbia, has supported the idea of diagnostic substitution wherein a child who would have been classified as having an ID or DD in the past is now being diagnosed with ASD. Diagnostic accretion, where a child is getting a diagnosis of ASD in addition to an existing diagnosis, has also been hypothesized as a partial cause of increased prevalence. King and Bearman (2009) found that from 1992 to 2005, 9% of ASD cases in California arose from diagnostic accretion or substitution. Some studies have had results that go against these hypotheses, finding no increase in ASD prevalence in step with an equal decrease in ID prevalence (Boyle et al., 2011; Grether et al., 2009).

According to the National Center for Education Statistics, 13.1% or 6.48 million school-aged youth aged 6-21 in the United States received special education services in the 2009-2010 school year (Snyder & Dillow, 2012). This percentage has decreased slightly since 2000 (13.3% to 13.1%) (Snyder & Dillow, 2012) which is in contrast to the increase in ASD prevalence over that time period(Autism and Developmental Disabilities Monitoring Network, 2014).. If the rise in ASD prevalence coincided with these children all receiving a first special educational exceptionality for autism, a rise in special education services would be expected. Since this has not been the case, these new cases of ASD may be coming from children who do not have special education exceptionality or had a prior exceptionality type, which would suggest diagnostic accretion or substitution.

Special education data in the United States are often used to as proxy data to enumerate disability prevalence (Maenner & Durkin, 2010). Unfortunately, special education data alone likely underrepresents ASD. Using ADDM data from the Utah site, Pinborough-Zimmerman and colleagues (2012) found that of children receiving a diagnosis of ASD through medical evaluations, 20-50% did not receive special education services. Special education records did provide a measurable impact on overall prevalence of ASD in Utah but not to the extent that health records did (Pinborough-Zimmerman et al., 2012). This further implies that the rise in ASD may not be entirely attributable to the population already with special education exceptionality but rather to an undiagnosed group not receiving school services.

In a study conducted in Wisconsin by Manner and Durkin (2010), the use of the autism exceptionality in elementary schools was found to have increased from 4.9 cases per 1000 students to 9.0 cases per 1000 students between 2002 and 2008. This increase was attributed to an increase in autism classification from schools that had the lowest prevalence of cases in the first surveillance year. This may imply that the increase in prevalence may be partially caused by an increase in awareness of ASD in areas that formerly had few diagnoses (Maenner & Durkin, 2010) and illustrates the importance of geographic clustering in exceptionality type. Different states, counties, and school districts will have different approaches to classification and accounting for those differences is vital in order to have unbiased results.

The purpose of this study is to evaluate trends in special education exceptionality for children with ASD identified by the ADDM network. Trends in exceptionality type stratified by sex and race/ethnicity will be assessed in order to evaluate possible

disparities. Results will be compared to publicly available IDEA data, a national count of special education participation collected by state. This will be done to assess how trends in exceptionality amongst children with ASD identified by the ADDM network compare to trends in exceptionality in all US eight-year olds. Our first hypothesis is that the prevalence of autism and DD exceptionalness will significantly increase while ID exceptionality will significantly decrease over the study period. Secondly, we hypothesize that females and children of Hispanic ethnicity will have higher frequency of ID exceptionality compared to males and non-Hispanics and there will be significant decreasing trend. We believe that the broader IDEA sample will show a slower decrease in ID exceptionality and a larger increase in autism exceptionality as compared to the ADDM sample of only children with ASD.

2.2 Methods

Data from the ADDM network, a multi-source surveillance system established by the Centers of Disease Control and Prevention in 2000, were used for this study (Autism and Developmental Disabilities Monitoring Network, 2014). Sixteen sites have contributed to the ADDM network over the surveillance period (Alabama, Arkansas, Arizona, Colorado, Florida, Georgia, Illinois, Maryland, Missouri, North Carolina, New Jersey, Pennsylvania, South Carolina, Utah, Wisconsin, and West Virginia). This study includes only sites that contributed data to 2002, 2006, and 2008; 2000 and 2004 were excluded due to poor site participation and scarcity of data. Since special education status was examined, sites that did not abstract school records were excluded. Each site met their local institutional review board requirements.

2.2.a Data collection and ASD case status

A variety of educational and health records were abstracted in order to determine ASD case status. Medical, behavioral, psychiatric, and developmental histories, as well as symptoms and diagnoses consistent with DSM-IV-TR were collected for each child along with all available school records. Then, a research-trained clinician used a highly structured scoring protocol based on the DSM-IV-TR to ascertain ASD status using the collected records. In 2008, inter-rater reliability was established for all sites and maintained on a random sample of greater than 10% of abstracted records: overall agreement was 90.2%, and kappa was .8 (Autism and Developmental Disabilities Monitoring Network, 2012). Primary special education exceptionality was denoted in school records and was categorized into twelve categories based on the IDEA. The ADDM network classification of exceptionalities combined deafness, deaf-blindness, hearing impairment, and vision impairment into a hearing / vision impairment category and has an 'other' exceptionality. Categories were exclusive and only one primary exceptionality was listed per child.

2.2.b Comparison data

National data were collected from IDEA part B that mandates data collection on all special education services provided by schools. Data collected from eight-year-old children was used. Each exceptionality category is presented as a percentage of all children with exceptionality. IDEA data is presented using both the national data and after weighting to approximate the site contributions of the ADDM data used. Weighting was done by using IDEA data from only states that had sites selected for this study. IDEA data from each state for a give study year was multiplied by the percent of this

studies sample contributed by said site for the given year. Chi square tests were used to test for trend in each exceptionality.

2.2.c Data analyses

Analyses were conducted using Stata 12.1 (College Station, Texas). To evaluate trends, rare event logistic regression was used with a significance level of $P< 0.05$. Rare events logistic regression was chosen in order to account for exceptionalities with very low frequency (M. King & Bearman, 2009). Due to differing study staff and state reporting requirements, site was controlled for using a cluster option in the regression model. The 2002 surveillance year was used as a reference group and t-tests were conducted to compare change from 2002 to 2006 to the change from 2002 to 2008 (change was determined from the regression model); if the difference was significant at a $P < 0.05$ level overall trend was deemed significant. This analytical method was repeated after stratification by sex and three-category race (white non-Hispanic, black non-Hispanic, and Hispanic. An interaction term for sex or race/ethnicity and study year was added to the total sample regression models to test the multiplicative effects of sexes or race/ethnicities over time. Regression models were not able to handle instances where there were no cases in a surveillance year.

2.3 Results

Table 2.1 illustrates descriptive statistics and age at first diagnosis for 4,176 children who met entry criteria for this study. There were 513 children who had ADDM identified ASD but no notation of exceptionality on their records; they are not included in the 4,176-child sample. Over the three surveillance years, percentage of children with Hispanic ethnicity increased from 7.8% in 2002 to 11.7% in 2008. White race, non-

Hispanic decreased from 58.4% to 50.8% over the same interval. Age at first diagnosis also decreased from 63.5 months in 2002 to 57.3 months in 2008.

Frequency, percent of all children with ASD and a specific exceptionality given any exceptionality, percent change from 2002-2008, and P values are presented for the total sample in table 2.2. The most frequent exceptionality for children with ASD in all three surveillance years was autism; this exceptionality type increased slightly (5.58%) from 2002 to 2008, but not significantly (P=.22). There was a significant negative trend in ID (38.1% decrease from 2002-2008, P< .001). DD had the largest percentage increase of all exceptionalities from 2002 to 2008 (974%) and was the only one to increase significantly (P< .001). Figure 2.1 presents the exceptionalities with proportion greater than 5% of all exceptionalities for the total sample.

Table 2.3 present exceptionality trends stratified by sex. For males with ADDM identified ASD, there was a significant negative trend in ID exceptionality (-37% from 2002-2008, P< .001). DD exceptionality had the largest percent increase from 2002-2008 (996%) and was the only exceptionality to significantly increase (P< .001). Autism was the most frequent exceptionality for both males and females with ASD for all three surveillance years; however, there was a significant increase in autism exceptionality only for females with ASD (7.1% increase, P< .001). Trend in autism exceptionality significantly differed between males and females (P=.008). ID exceptionality significantly decreased for females with ASD (P<.001) and this decrease was significantly greater than in males with ASD (P< .001). Females with ASD had a significant increase in DD (90%, P=.0014) and other health impairment (33.3%, P=

.0047). There was no significant difference between trend for males and females in DD (P=.376)

Table 2.4 shows results stratified by race / ethnicity. There were no significant trends in autism exceptionality for the three subgroups and the interaction covariate was not significant (P= .085). White, non-Hispanic children with ASD had a significant increasing trend for other health impairment exceptionality (49.3% increase from 2002 to 2008, P= .0013). White, non-Hispanic and black, non-Hispanic children with ASD had a significant decreasing trend for ID (P=.0027, P< .001 respectively), whereas trend for Hispanic children with ASD did not meet significance (P=.23). Overall, the interaction term for race/ ethnicity and study year was significant (P= .0223). Like the total population and groups stratified by sex, DD had the largest increase in percentage for all three race / ethnicity groups, and met significance for the white, non-Hispanic (1062.2% increase, P< .001), black, non-Hispanic (566.66% increase, P= .0043), and Hispanic children (300% increase, P< .001) although there were no Hispanic children with DD in 2002. The race/ethnicities did not significantly differ (P=.691) based on the interaction term. Black, non-Hispanic children with ASD had an additional increasing trend in multiple disabilities (75% increase, P< .001) while Hispanic children with ASD had a decreasing trend in specific learning disability (29.5% decrease, P< .001).

IDEA data are presented for the entire US in table 2.5.There are significant decreasing trends for ID (-22.6%, P< .001), speech or language impairments (-.5%, P< .001), emotional disturbance (-14.5%, P< .001), orthopedic impairments (-20.5%, P< .001), specific learning disabilities (-16.1%, P< .001), and multiple disabilities (-15.3%, P< .001) from 2002 to 2008. Trends increased for other health impairments

Table 2. 1 Frequency and percentage of demographic variables from ADDM identified ASD cases with special education exceptionality

	2002	2006	2008
	N=927 n (%)	N=1460 n (%)	N=1789 n (%)
Sex			
Male	762 (82.2)	1219 (83.5)	1504 (84.1)
Female	165 (17.8)	241 (16.5)	285 (15.9)
Race			
White, non-Hispanic	541 (58.4)	785 (53.8)	909 (50.8)
Black, non-Hispanic	255 (27.5)	348 (23.8)	489 (27.3)
Hispanic	83 (7.8)	201 (12.4)	234 (11.7)
Other or Missing	48 (5.2)	126 (8.6)	157 (8.8)
Site			
Arizona	252 (27.2)	475 (32.5)	480 (26.8)
Colorado	40 (4.3)	41 (2.8)	77 (4.3)
Georgia	309 (33.3)	425 (29.1)	554 (31)
Maryland	103 (11.1)	158 (10.8)	214 (12)
North Carolina	121 (13.1)	197 (13.5)	261 (14.6)
South Carolina	102 (11)	164 (11.2)	203 (11.4)
Age at first diagnosis in months (% missing)			
	63.5 (43)	57 (38)	57.3 (37)

Table 2. 2: Trends in special education exceptionalities for all ADDM identified ASD cases with exceptionality, 2002, 2006, and 2008

Exceptionality	2002 N=927	2006 N=1460	2008 N=1789	P Value for trend	% Change 2002-2008
	n (%)	n (%)	n (%)	n (%)	n (%)
Autism	515 (55.6)	831 (56.9)	1050 (58.7)	.22	5.57
Emotional Disturbance	58 (6.3)	57 (3.9)	74 (4.1)	.17	-35.0
Specific Learning Disability	72 (7.8)	104 (7.1)	121 (6.8)	.54	-12.8
Speech language Impairment	79 (8.5)	116 (7.9)	123 (6.9)	.28	-18.8
Hearing / Visual Impairment	-	2 (0.14)	3 (0.17)	-	-
Orthopedic Impairment	10 (1.1)	10 (0.69)	23 (1.3)	.17	18.2
Traumatic Brain Injury	1 (0.11)	-	1 (0.06)	-	-45.5
Other Health Impairment	55 (5.9)	121 (8.3)	124 (6.9)	.10	15.0
Multiple Disabilities	15 (1.6)	26 (1.8)	27 (1.5)	.82	-6.3
Intellectual Disability	117 (12.6)	141 (9.7)	139 (7.8)	**< .001**	-38.1
Developmental Delay	5 (0.54)	52 (3.6)	103 (5.8)	**< .001**	974.0
Other	-	-	1 (0.06)	-	-

Exclusive categorizes, deaf-blindness is encompassed in hearing /visual impairment

(43.4%, P< .001), autism (116.7%, P< .001), and DD (86.1%, P< .001) in the same time period. It should be noted that the large sample size may have influenced the significance of the results. Trends in exceptionalities with proportion > 5% for a given year are presented in figure 2.2. Table 2.6 and figure 2.3 present IDEA data for only states that participated in ADDM. IDEA data were selected from states in the ADDM network that contributed data to this study and were then weighted based on the proportion of children contributed by each ADDM network site for the given surveillance year. When comparing the national IDEA data to the IDEA data after weighing, increase in autism exceptionality for the total eight-year-old population was slightly higher (136.6% increase, P< .001) in the weighted subsample than the national data (116.7%) and decrease in ID exceptionality was slightly lower (-28.1%, P=.047). These were the only two exceptionalities to reach significance in the weighted subsample

2.4 Discussion

This study is unique in its analysis of trends in special education exceptionality for children with ASD. In learning more about special education classification patterns, services can be better appropriated to children with ASD, specifically underrepresented groups (like female, black, and Hispanic children). ID exceptionality decreased in the total sample; this is in agreement with the overall trend in decreased co-occurring ID in ASD (Autism and Developmental Disabilities Monitoring Network, 2014; Fombonne, 2005). When assessing trend in ID exceptionality across subgroups, certain patterns emerge. ID exceptionality decreased amongst both males and females with ASD, but decreased faster amongst females. ID significantly decreased for white and black non-Hispanic subgroups; further investigation into site specific clustering should be

Table 2.3 Trends in special education exceptionalities stratified by sex in ADDM identified children with ASD and exceptionality, 2002, 2006, and 2008

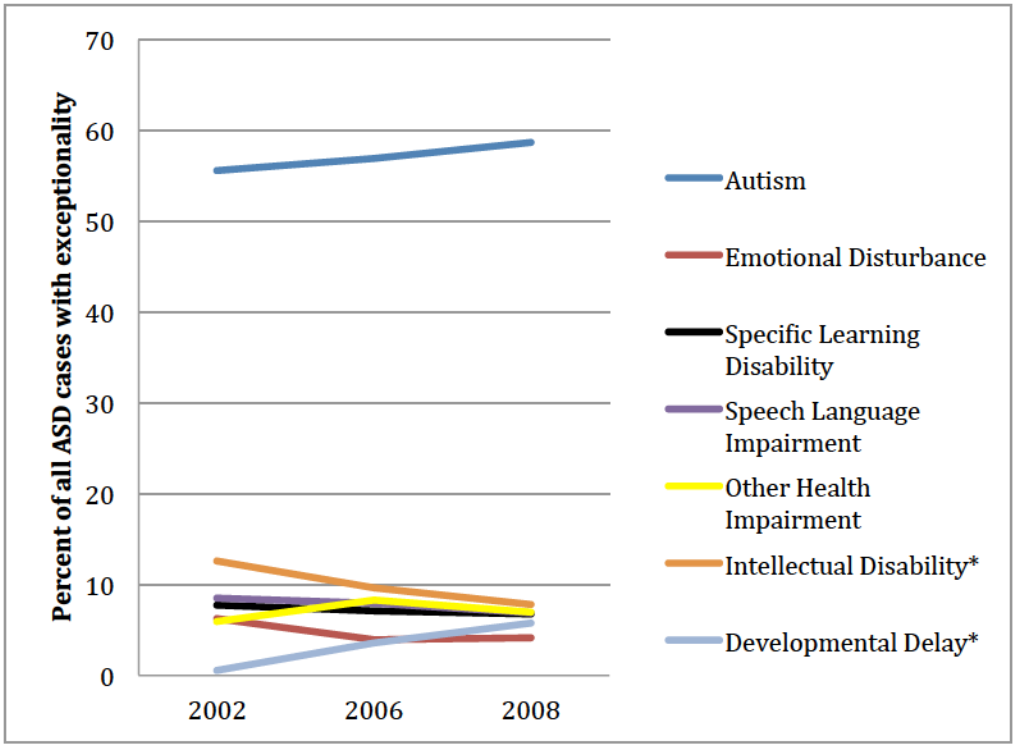
	Male					Female				
Exceptionality	**2002 N=762**	**2006 N=1219**	**2008 N=1504**	**P Value for trend**	**% Change 2002-2008**	**2002 N=165**	**2006 N=241**	**2008 N=285**	**P Value for trend**	**% Change 2002-2008**
	n (%)	**n (%)**	**n (%)**			**n (%)**	**n (%)**	**n (%)**		
Autism*	429 (56.3)	719 (59.0)	891 (58.5)	.34	3.9	86 (52.1)	112 (46.5)	159 (55.8)	**< .001**	7.1
Emotional Disturbance	48 (6.3)	45 (3.7)	60 (4.0)	.19	-36.5	10 (6.1)	12 (5.0)	14 (4.9)	.89	-20.0
Specific Learning Disability	59 (7.7)	91 (7.5)	101 (6.7)	.72	-13.0	13 (7.9)	13 (5.4)	20 (7.0)	.67	-11.4
Speech/Language Impairment	67 (8.8)	92 (7.6)	107 (7.1)	.65	-19.3	12 (7.3)	24 (10.0)	16 (5.6)	**.023**	-23.3
Hearing / Visual Impairment	-	1 (0.08)	2 (0.13)	-	-	-	1 (0.41)	1 (0.35)	-	-
Orthopedic Impairment	10 (1.3)	10 (.82)	19 (1.3)	.28	0	-	-	4 (1.4)	-	-
Traumatic Brain Injury	1 (0.13)	-	1 (0.07)	-	-46.2	-	-	-	-	-
Other Health Impairment	48 (6.3)	98 (8.0)	108 (7.2)	.31	14.3	7 (4.2)	23 (9.5)	16 (5.6)	**.0047**	33.3
Multiple Disabilities	10 (1.3)	16 (1.3)	22 (1.5)	.93	15.4	5 (3.0)	10 (4.2)	5 (1.8)	.056	40.0
Intellectual Disability*	86 (11.3)	105 (8.6)	107 (7.1)	**< .001**	-37.2	31 (18.8)	36 (14.9)	32 (11.2)	**< .001**	-40.0
Developmental Delay	4 (0.52)	42 (3.5)	86 (5.7)	**< .001**	996.1	1 (0.61)	10 (4.2)	17 (6.0)	**.0014**	90.0
Other	-	-	-	-	-	-	-	1 (0.35)	-	-

Table 2. 4 Trends in special education exceptionalities stratified by race / ethnicity for children with ASD and exceptionality identified by the ADDM network, 2002, 2006, and 2008

	White, non-Hispanic					Black, non-Hispanic					Hispanic				
Exceptionality	**2002 N=541**	**2006 N=785**	**2008 N=909**	**P Value for trend**	**% Change 2002-2008**	**2002 N=255**	**2006 N=348**	**2008 N=489**	**P Value for trend**	**% Change 2002-2008**	**2002 N=83**	**2006 N=201**	**2008 N=234**	**P Value for trend**	**% Change 2002-2008**
	n (%)	**n (%)**	**n (%)**			**n (%)**	**n (%)**	**n (%)**			**n (%)**	**n (%)**	**n (%)**		
Autism	303 (56.0)	451 (57.5)	525 (57.8)	.76	3.21	155 (60.8)	212 (60.9)	312 (63.4)	.16	4.3	33 (39.8)	89 (44.3)	106 (45.3)	.34	13.9
Emotional Disturbance	40 (7.4)	40 (5.1)	42 (4.6)	.45	-37.8	11 (4.3)	11 (3.2)	14 (2.9)	.73	-32.6	4 (4.8)	4 (2.0)	12 (5.1)	.073	6.2
Specific Learning Disability	40 (7.4)	49 (6.2)	58 (6.4)	.54	-13.5	16 (6.3)	22 (6.3)	33 (6.8)	.96	7.9	9(10.9)	23 (11.4)	18 (7.7)	**<. 001**	-29.5
Speech Language Impairment	55 (10.2)	64 (8.2)	69 (7.6)	.59	-25.5	13 (5.1)	21 (6.0)	20 (4.1)	.48	-19.6	8 (9.6)	17 (8.4)	26 (11.1)	.69	15.7
Hearing or Visual Impairment	-	-	2 (0.22)	-	-	-	-	-	-	-	-	2 (1.0)	-	-	-
Orthopedic Impairment	7 (1.29)	4 (.51)	17 (1.87)	.11	45.0	2 (0.8)	2 (0.6)	2 (0.4)	**<. 001**	-50	-	3 (1.5)	3 (1.28)	-	-
Traumatic Brain Injury	1 (0.18)	0 (0.0)	1 (0.11)	-	-38.9	-	-	-	-	-	-	-	-	-	-
Other Health Impairment	36 (6.7)	83 (10.6)	91 (10.0)	**.0013**	49.3	12 (4.7)	14 (4.0)	19 (3.9)	.72	-17	4 (4.8)	12 (6.0)	10 (4.3)	.63	-10.4
Multiple Disabilities	11 (2.0)	16 (2.0)	16 (1.8)	.66	-10.0	2 (0.8)	2 (0.6)	7 (1.4)	**< .001**	75	2 (2.4)	6 (3.0)	2 (0.85)	**< .001**	-64.5
Intellectual Disability *	46 (8.5)	56 (7.1)	48 (5.3)	**.027**	-37.6	41 (16.1)	41 (11.8)	43 (8.8)	**< .001**	-45.3	21 (25.3)	33 (16.4)	35 (14.9)	.23	-41.1
Developmental Delay	2 (.37)	22 (2.8)	39 (4.3)	**<. 001**	1062.2	3 (1.2)	23 (6.6)	39 (8.0)	**.0043**	566.6	-	2 (1.0)	11 (4.7)	**< .001^**	370^
Other	-	-	1 (0.11)	-	-	-	-	-	-	-	-	-	-		-

* P <.05 for test of multiplicative effects for the three groups
^ due to the lack of cases in 2002, 2006 was compared to 2008

Figure 2. 1 Trends in proportion for exceptionality types for children with ASD and special education exceptionality in ADDM if proportion is >5% for a given surveillance year, 2002, 2006, and 2008



* Indicates significant trend

conducted to examine why this trend did not meet significance in Hispanic children with ASD. The decrease in ID exceptionality was significantly greater in black children as compared to white children.. These results are noteworthy because it has consistently been seen that co-occurring ID is more prevalent in girls, blacks, and Hispanics with ASD as compared to males and white children (Autism and Developmental Disabilities Monitoring Network, 2012; Banach et al., 2009; Lecavalier, Snow, & Norris, 2011). The greater change in ID exceptionality for children with ASD in these subgroups may be a manifestation of an improving recognition of ASD and DD in under-represented groups.

There were no significant percent of children with ASD and an autism exceptionality in the total sample . Female children with ASD had a significant but small increase in autism exceptionality but this may have be impacted by the smaller sample size and unaccounted clustering effects; The trend in autism exceptionality for females was significantly different than the trend in males. Again, this may suggest that schools have improved in recognized the female ASD phenotype. Percent with autism exceptionality was highest for black and non-Hispanic children with ASD as compared to white children with ASD for all three surveillance years but difference in trend was not significant. The lack of increase in autism exceptionality may imply that there is still a subset of children that are being misidentified or that diagnostic substitution or accretion has occurred.

DD exceptionality increased for the total sample and each subgroup. This was to be expected as DD exceptionality was only added to the IDEA in 1997 (108th United States Congress, 2004). Therefore, the increasing trend is to be expected as schools became more familiar with the usage of the exceptionality. Additionally, the practice of

early developmental screening has risen over the time span of this study (Arunyanart et al., 2012; Radecki et al., 2011; Wiggins, Piazza, & Robins, 2014). Developmental screening is recommend to take place at 9, 18, 24, and 30 months; ASD screening is recommended at 18 and 24 months (Council on Children With Disabilities Section on Developmental Behavioral Pediatrics Bright Futures Steering Committee Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006). With more developmental screening at earlier ages, it becomes more likely that children will receive a DD diagnosis prior to being diagnosed with ASD; this may affect exceptionality classification. Some studies have found that pediatricians do not screen for ASD as frequently as they do DD (Dosreis, Weiner, Johnson, & Newschaffer, 2006) and non-white children are more likely to be screened for DD and less likely to be screened for ASD compared to white children (Arunyanart et al., 2012). We did not find a significant difference between the race/ethnicities in DD trend, but our sample was sparse. Further research should be done with a more robust sample to determine the effect of early screening on DD exceptionality.

It is necessary to compare trends in the ADDM data to IDEA data in order to determine whether trends in special education exceptionality for children with ASD are a reflection of trends in the total eight-year-old population (with and without ASD). Compared to the ADDM data, IDEA data had a larger and statistically significant increase in autism exceptionality. The change in the IDEA data reflects the rise in ASD prevalence while the stagnancy of the ADDM data reflect the lack of change in likelihood of a child with ASD getting an autism exceptionality. Additionally, IDEA data suggest that autism is contributing a larger percentage of all exceptionalities for children with any

exceptionality. Large increases in DD and decreases in ID were found in both ADDM data and national and state weighted IDEA data. This may imply that the increase in DD exceptionality as seen in the ADDM network is a reflection of the increase in the usage of the exceptionality in all children. Further exploration is needed to determine whether a child with ASD is more likely to get a DD exceptionality as compared to any child with exceptionality. The decrease in ID exceptionality may partially be a function of diagnostic substitution to DD.

Limitations of this study include the exclusive nature of special education exceptionality. In many cases, children meet criteria for more than one exceptionality but only one can be the 'primary' exceptionality. This limits our ability to identify all children who receive services for ASD and to assess diagnostic accretion or substitution. Furthermore, this study did not restrict study sites to those that obtained IQ data. With that information, diagnostic substitution from ID to either autism or DD exceptionalities could have been better assessed. A larger sample, particularly with a greater amount of females, would have provided for the ability to perform additional trend tests and possibly test sex by race interaction. In regard to IDEA data, it was not possible to match the sample area to the ADDM area due to data availability and privacy issues. Using states that had sites for this study and weighing based on the sample population was our best approximation for matching sampling areas. Time of exceptionality classification was unknown so possible issues of temporality arise. If we were able to ascertain when a classification was given in relation to an ASD diagnosis, we could better understand the role of expanded screening practices and other cohort effects.

To our knowledge, this is the first study to assess trends in special education exceptionality in children with ASD from multiple sites. Stratifying results by sex and race/ethnicity allow for a closer examination into possible classification disparities. Additionally, the usage of the IDEA data allow us to better grasps which trends are a function of changes in classifying children with ASD as compared to all children with exceptionality.

2.5 Conclusions

In children with ASD identified by ADDM and special education exceptionality in 2002, 2006, and 2008, autism exceptionality did not significantly change. This lack of change was seen for each race/ethnicity subgroup; however, females had a significant increase in autism exceptionality, which differed from males. ID classification significantly decreased for both sexes with females having a significantly greater decline than males. ID exceptionality decreased significantly for white and black children and black children had a greater decline. These results may imply that schools are becoming better at identifying non-ID exceptionalities in underrepresented subgroups. DD exceptionality increased for all subgroups and the increase may be partially attributable to more frequent early developmental screening. Additional research that incorporates IQ data and when the child was classified should be conducted to further assess diagnostic substitution and accretion of special education exceptionality.

Table 2. 5 Percent of eight-year-old children in the US with a certain exceptionality, given that they have an exceptionality from IDEA part B data

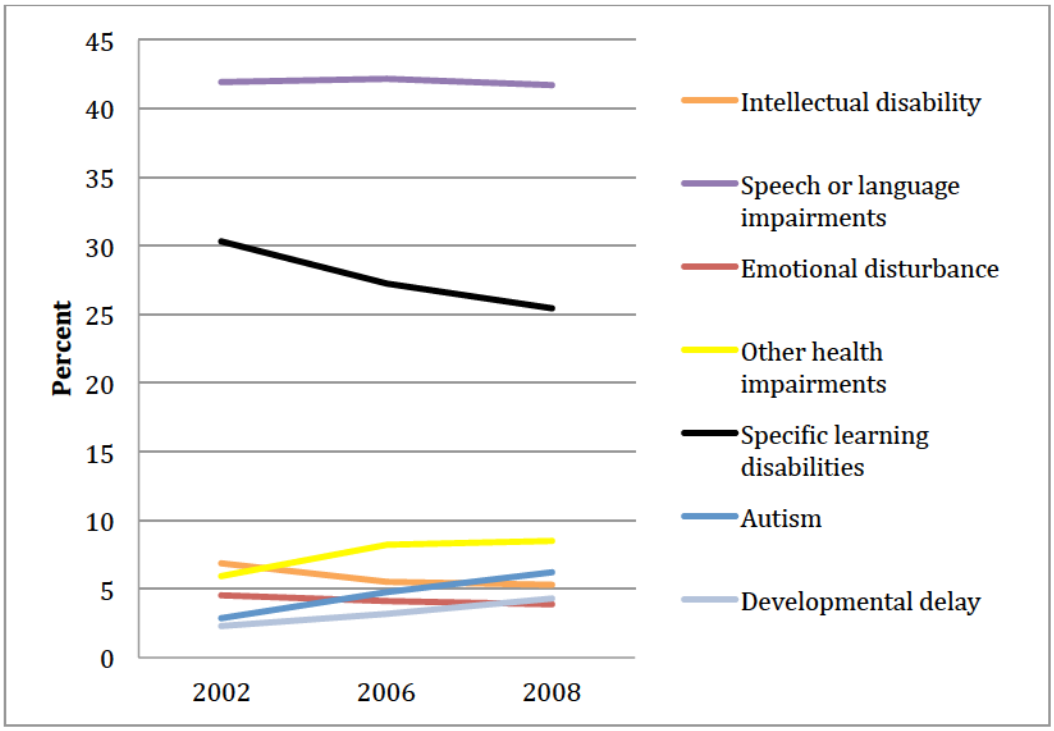
Exceptionality type	2002 N=451,214	2006 N=460,379	2008 N=456,526	% Change 2002-2008	X^2	P value
Intellectual Disability	6.86	5.54	5.31	-22.6	17771	**< .001**
Hearing or Visual Impairment	1.22	1.17	1.17	-5	6.9	0.07
Speech or Language Impairment	41.93	42.17	41.71	-.5	343	**< .001**
Visual Impairments	0.43	0.43	0.43	0	11.8	**0.008**
Emotional Disturbance	4.54	4.12	3.88	-14.5	448.6	**< .001**
Orthopedic Impairments	1.32	1.07	1.05	-20.5	314.6	**< .001**
Other health Impairments	5.94	8.22	8.52	43.4	4033	**< .001**
Specific learning Disabilities	30.34	27.24	25.45	-16.1	5327	**< .001**
Deaf-blindness	0.02	0.02	0.03	50	3.1	0.4
Multiple Disabilities	1.96	1.76	1.66	-15.3	188.2	**< .001**
Autism	2.87	4.78	6.22	116.7	11539.4	**< .001**
Traumatic Brain Injury	0.26	0.27	0.28	7.7	3.7	0.3
Developmental Delay	2.31	3.20	4.30	86.1	6575	**< .001**

* (Exceptionality categorization does not match up perfectly with ADDM categorization)

Table 2.6: IDEA data for states that contributed ADDM data and were selected for this study, weighted by proportion of children from that site in the given surveillance year

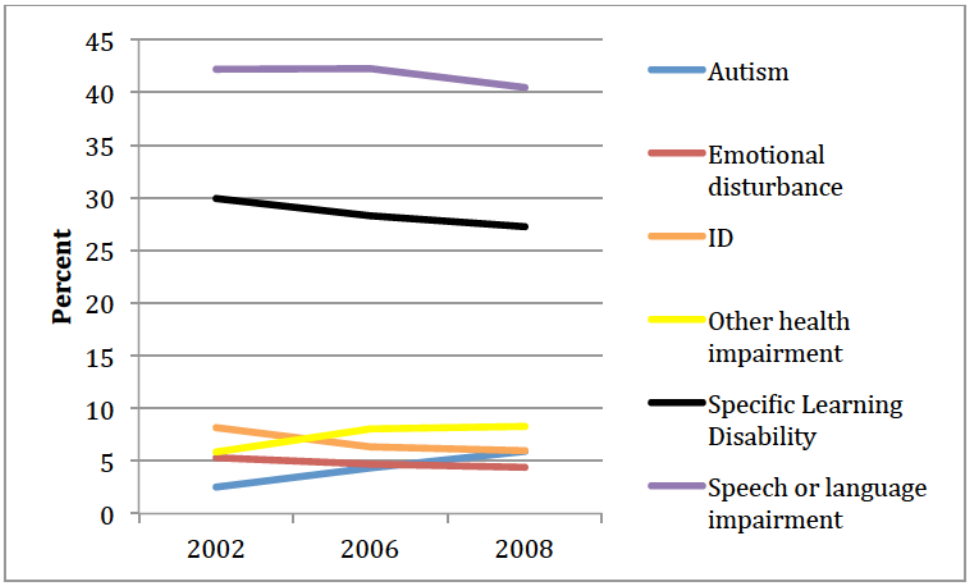
Exceptionality	2002	2006	2008	%Change 2002-2008	X^2	P Value
Autism	2.68	4.51	6.34	136.6	18.3	**<. 001**
Emotional Disturbance	6.03	5.18	4.65	-22.9	2.4	.30
ID	9.15	7.11	6.58	-28.1	6.1	**.047**
Other health impairment	6.64	8.81	8.99	35.9	4.9	.088
Specific Learning Disability	32	31.3	30	-6.3	1.2	.54
Speech or Language Impairment	42.9	42.5	40.2	-6.3	2.7	.26

Figure 2. 2 Trends in exceptionality for all eighty-year-old children with exceptionality from IDEA national data



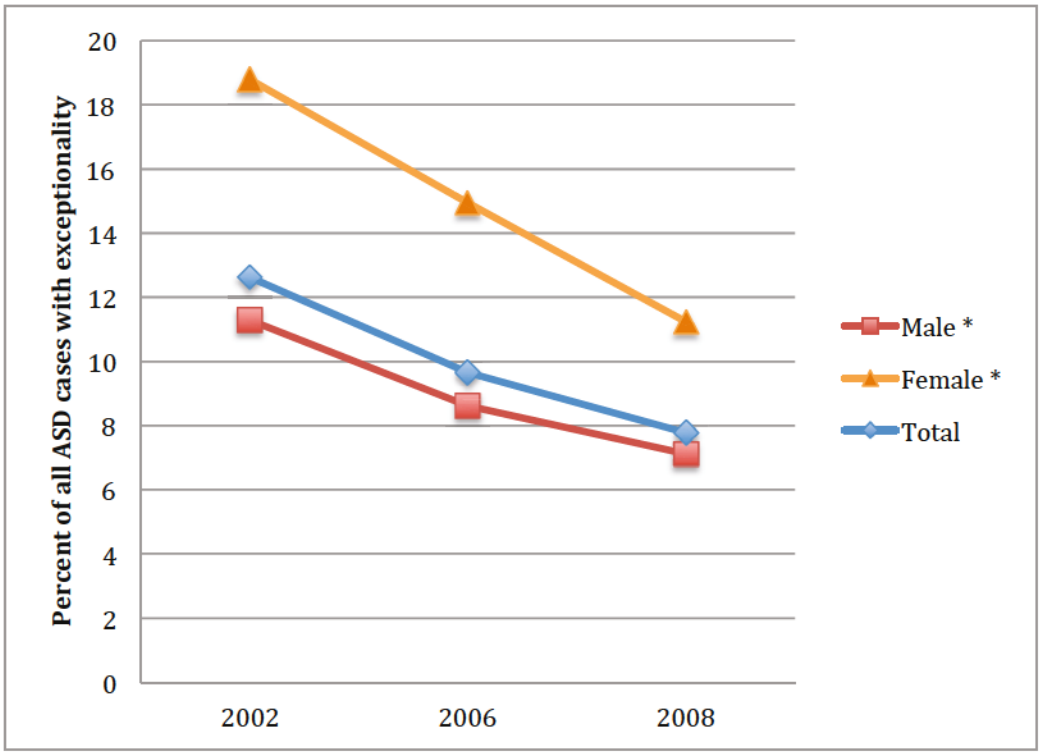
* All trends are significant, exceptionality is included if prevalence is >5% in at least one surveillance year

Figure 2. 3 Trends in IDEA exceptionality for all eight-year-old children with exceptionality from states that contributed to ADDM



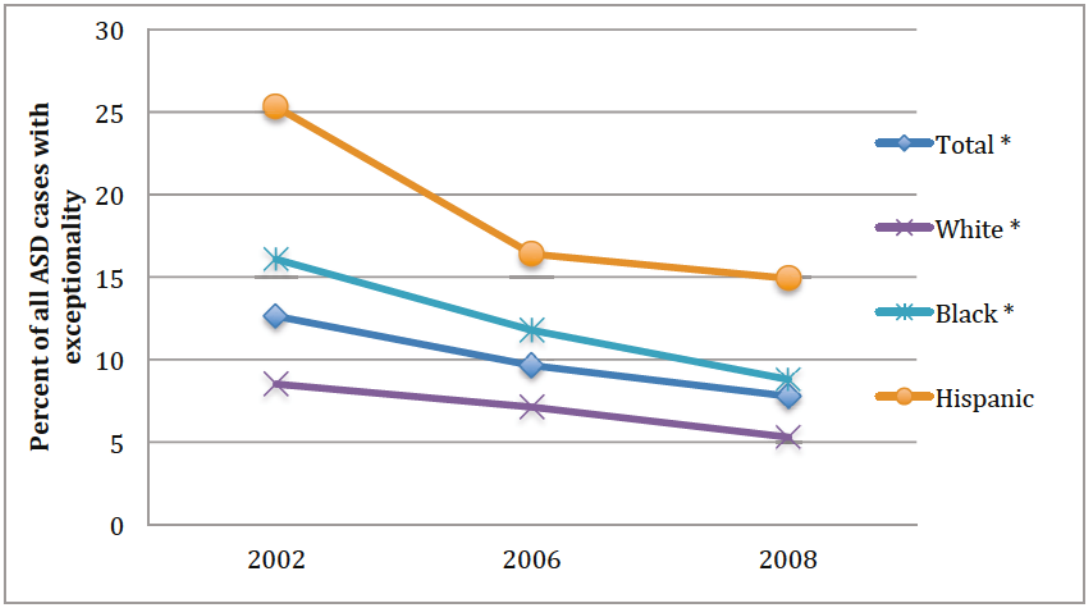
* Autism and ID exceptionality are significant

Figure 2. 4 Trends in ID exceptionality by sex for children with ASD identified by ADDM and any exceptionality



* All trends significant, Male and female significantly differ

Figure 2.5 Trends in ID exceptionality by race / ethnicity for children with ASD identified by ADDM and any exceptionality



* Indicates significance, trends significantly differ

Appendix

Table 1.6 Missing IQ data by sex and test for association over time

Sex	**2002** N= 59	**2006** N= 113	**2008** N= 117
	n (%)	n (%)	n (%)
F	12 (20.3)	22 (19.5)	19 (16.2)
M	47 (79.7)	91 (80.5)	98 (83.8)

Pearson chi^2 (2)= .5984 P=0.741

Table 1.7 Missing IQ data by site and test for association over time

Site	**2002** N= 59	**2006** N= 113	**2008** N= 117
	n (%)	n (%)	n (%)
AZ	21 (35.6)	34 (22.8)	24 (2.1)
GA	23 (39.0)	40 (26.6)	40 (34.2)
NC	5 (8.5)	47 (31.5)	13 (11.1)
SC	10 (17.0)	28 (18.8)	40 (34.2)

Pearson chi^2 (6) = 32.67 **P <. 0001**

Table 1.8 Missing IQ data by previous documentation of ASD and test for association with time

Prior ASD diagnosis	**2002** N= 59	**2006** N= 113	**2008** N= 117
	n (%)	n (%)	n (%)
Yes	41 (69.5)	81 (71.7)	83 (70.9)
No	18 (30.5)	32 (28.3)	34 (29.1)

Pearson chi^2 (2) = .0902 P=. 956

Table 1.9 Missing IQ data by race / ethnicity and test for association with time

Race	**2002** N= 59	**2006** N= 113	**2008** N= 117
	n (%)	n (%)	n (%)
White, non-Hispanic	36 (61.0)	59 (52.2)	60 (51.3)
Black, non-Hispanic	15 (25.4)	23 (20.4)	29 (24.8)
Hispanic	4 (6.8)	14 (12.3)	9 (7.6)
Other, Missing	4 (6.8)	17 (15.0)	19 (16.2)

Pearson chi^2 (6) = 10.76, P=. 38

Table 1.10 Count and percent of children with ASD and given number of DACC in the ADDM network

	2002 N= 871	**2006** N= 1518	**2008** N= 1662	**% Change 2002-2008**
All children with ASD	n (%)	n (%)	n (%)	
0	202 (23.2)	400 (26.4)	248 (14.9)	-36
1	229 (26.3)	328 (21.6)	412 (24.8)	-5.7
2	187 (21.5)	312 (20.6)	386 (23.2)	7.9
3+	253 (29.0)	478 (31.5)	616 (37.1)	28
If previously diagnosed				
0	109 (21.2)	162 (18.9)	149 (13.8)	-34.9
1	136 (26.4)	195 (22.8)	269 (25.0)	-5.3
2	108 (21.0)	196 (22.9)	257 (23.8)	13.3
3+	162 (31.5)	303 (35.4)	403 (37.4)	18.8
If not previously diagnosed				
0	93 (26.1)	103 (19.5)	99 (17.0)	-34.9
1	93 (26.1)	133 (25.2)	143 (24.5)	-6.5
2	79 (22.2)	116 (22.0)	129 (22.1)	-.4
3+	91 (25.6)	175 (33.2)	213 (36.5)	42.6
With ID				
0	66 (17.3)	91 (16.7)	51 (8.4)	-51.4
1	102 (26.7)	90 (16.5)	120 (19.8)	-25.8
2	84 (22.0)	127 (23.3)	147 (24.3)	10.4
3+	130 (34.0)	237 (43.5)	287 (47.4)	39.1
Without ID				
0	110 (25.6)	242 (29.4)	166 (17.7)	-30.1
1	111(25.8)	194 (23.52)	247 (26.3)	1.9
2	97 (22.6)	166 (20.2)	216 (23.0)	1.8
3+	112 (26.1)	222 (26.9)	311 (33.1)	26.8

Table 1.11 Risk ratios and confidence intervals for DACCs in the ADDM network

	Total sample		With prior documented ASD		Without prior documented ASD		With ID		Without ID	
Diagnosis	2006 vs. 2002	2008 vs. 2002	2006 vs. 2002	2008 vs. 2002	2006 vs. 2002	2008 vs. 2002	2006 vs. 2002	2008 vs. 2002	2006 vs. 2002	2008 vs. 2002
Categorized DACC										
Developmental	1.01 (.94-1.09)	**1.17 (1.09-1.25)**	0.97 (.90-1.05)	1.04 (.97-1.12)	**1.14 (1.01-1.28)**	**1.17 (1.04-1.31)**	1.08 (0.93-1.26)	**1.29 (1.12-1.48)**	**1.26 (1.15-1.38)**	0.94 (0.85-1.03)
Psychiatric	.75 (.53-1.05)	.89 (.65-1.22)	0.85 (.55-1.33)	.99 (.65-1.49)	.78 (.47-1.32)	.76 (.45-1.26)	0.76 (0.34-1.71)	0.57 (0.25-1.34)	0.95 (0.65-.1.39)	0.76 (0.53-1.09)
Neurological	1.25 (.81-1.92)	1.19 (.77-1.83)	1.60 (.94-2.73)	1.14 (.66-1.96)	.92 (.43-1.98)	1.27 (.63-2.58)	1.10 (0.59-2.02)	.87 (.46-1.63)	**2.51 (1.10-5.72)**	1.46 (0.64-3.32)
Possible Causative Medical	0.23 (.045-1.18)	0.63 (.19-2.05)	0.60 (.037-9.60)	3.76 (.39-36.1)	.17 (.019-1.50)	.46 (.10-2.03)	0.35 (0.03-3.85)	0.32 (.029-3.47)	-	1.14 (0.12-10.89)
Individual DACCs										
ADHD	0.82 (.63-1.06)	1.03 (.81-1.32)	0.84 (.60-1.16)	1.13 (0.84-1.53)	1.00 (.66-1.53)	0.79 (0.51-1.23)	0.63 (0.34-1.18)	1.07 (.63-1.84)	1.13 (.82-1.55)	0.82 (0.60-1.11)
SDD Adaptive	1.05 (.89-1.23)	**1.37 (1.18-1.60)**	1.12 (.92-1.37)	**1.32 (1.10-1.60)**	**1.38 (1.06-1.80)**	**1.43 (1.11-1.86)**	1.05 (0.80-1.39)	**1.46 (1.13-1.88)**	**1.45 (1.14-1.85)**	1.17 (0.93-1.48)
SDD Cognitive	0.89 (.74-1.06)	1.17 (.99-1.38)	0.92 (.74-1.14)	0.96 (0.79-1.18)	1.19 (0.88-1.61)	**1.53 (1.15-2.04)**	0.86 (0.66-1.11)	**1.28 (1.01-1.62)**	**1.46 (1.07-2.00)**	**4.63 (3.41-6.30)**
SDD General	0.95 (.79-1.13)	.96 (.81-1.14)	1.06 (.86-1.32)	0.92 (0.74-1.14)	0.98 (0.71-1.34)	1.01 (0.75-1.37)	1.11 (0.85-1.45)	0.96 (0.73-1.27)	1.05 (.78-1.43)	**3.10 (2.30-4.20)**
SDD Language	1.09 (.94-1.26)	**1.22 (1.06-1.40)**	1.12 (.93-1.34)	1.10 (0.92-1.31)	1.16 (0.93-1.45)	**1.27 (1.03-1.58)**	1.21 (0.94-1.56)	1.25 (0.97-1.60)	1.14 (.94-1.39)	0.85 (0.711-1.03)
SDD Motor	1.16 (.97-1.38)	**1.24 (1.04-1.47)**	1.22 (.98-1.51)	1.17 (0.96-1.45)	**1.36 (1.02-1.83)**	**2.11 (1.57-2.84)**	1.31 (0.95-1.82)	**1.50 (1.10-2.05)**	**1.43 (1.12-1.82)**	0.98 (0.77-1.25)
SDD Personal	0.99 (.83-1.19)	**1.28 (1.08-1.52)**	0.91 (.73-1.14)	1.11 (0.91-1.36)	**1.48 (1.08-2.02)**	**1.69 (1.25-2.29)**	1.06 (0.77-1.46)	1.17 (0.86-1.59)	**1.33 (1.04-1.71)**	1.11 (0.88-1.41)
ID	0.94 (.75-1.17)	0.91 (0.73-1.13)	1.04 (0.78-1.37)	0.81 (0.61-1.07)	1.01 (0.70-1.44)	1.11 (0.78-1.57)	-	-	-	-
Language Disorder	1.00 (0.85-1.18)	1.13 (0.96-1.32)	1.02 (0.83-1.25)	1.13 (0.93-1.38)	1.22 (0.94-1.59)	1.10 (0.84-1.43)	1.12 (0.82-1.53)	**1.37 (1.02-1.84)**	1.07 (0.86-1.32)	0.77 (0.62-0.95)
Learning Disorder	0.82 (0.56-1.18)	1.11 (0.78-1.56)	0.88 (0.28-1.62)	1.29 (0.75-2.23)	0.96 (0.67-1.37)	1.29 (0.93-1.79)	0.40 (0.12-1.36)	0.81 (0.30-2.16)	1.02 (0.69-1.51)	0.81 (0.56-1.17)

Figure 1. 2 Categorized distribution of DACCs in the ADDM Network

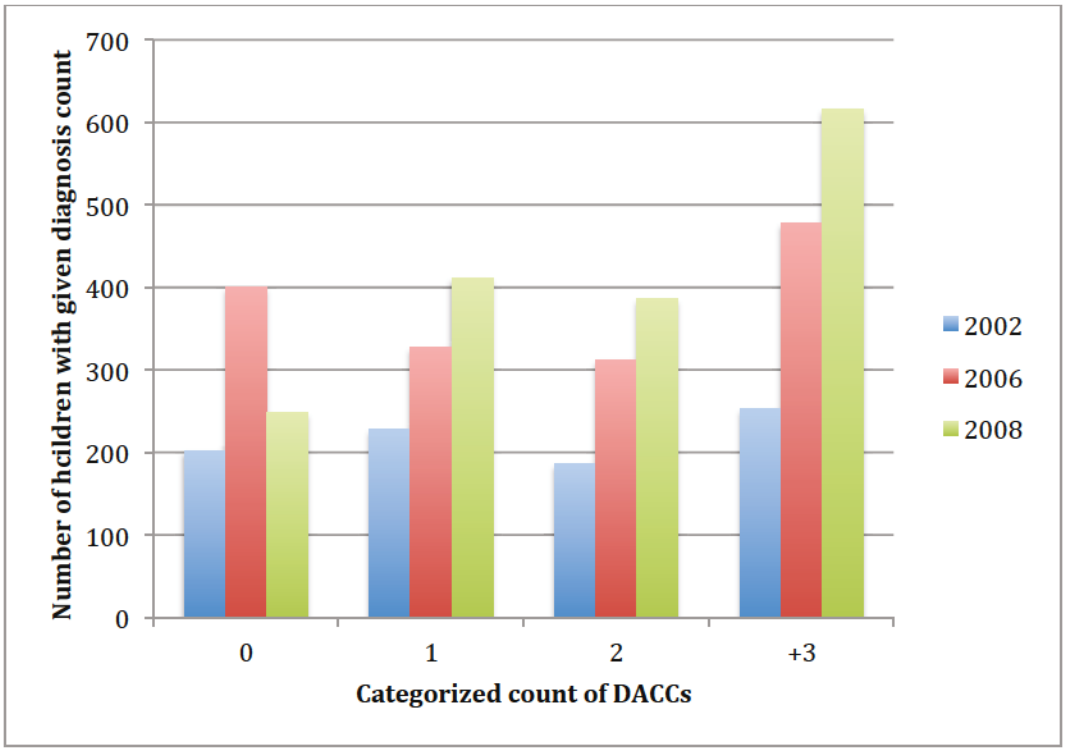
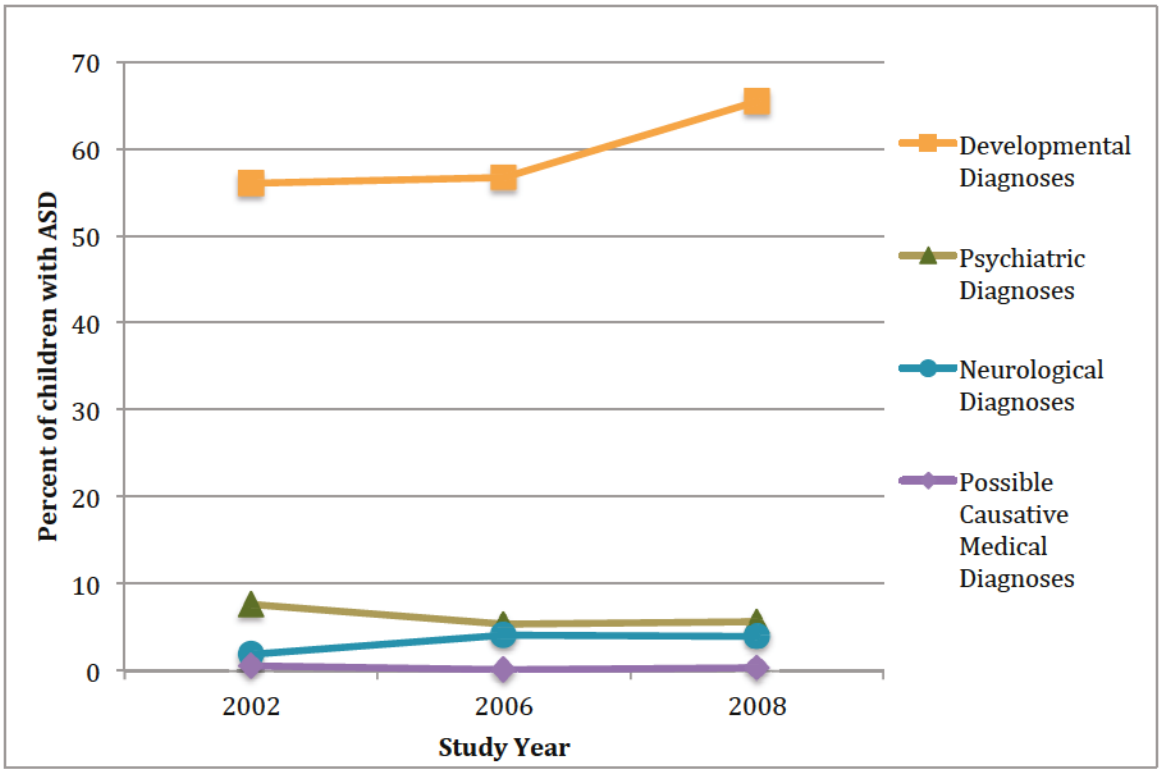
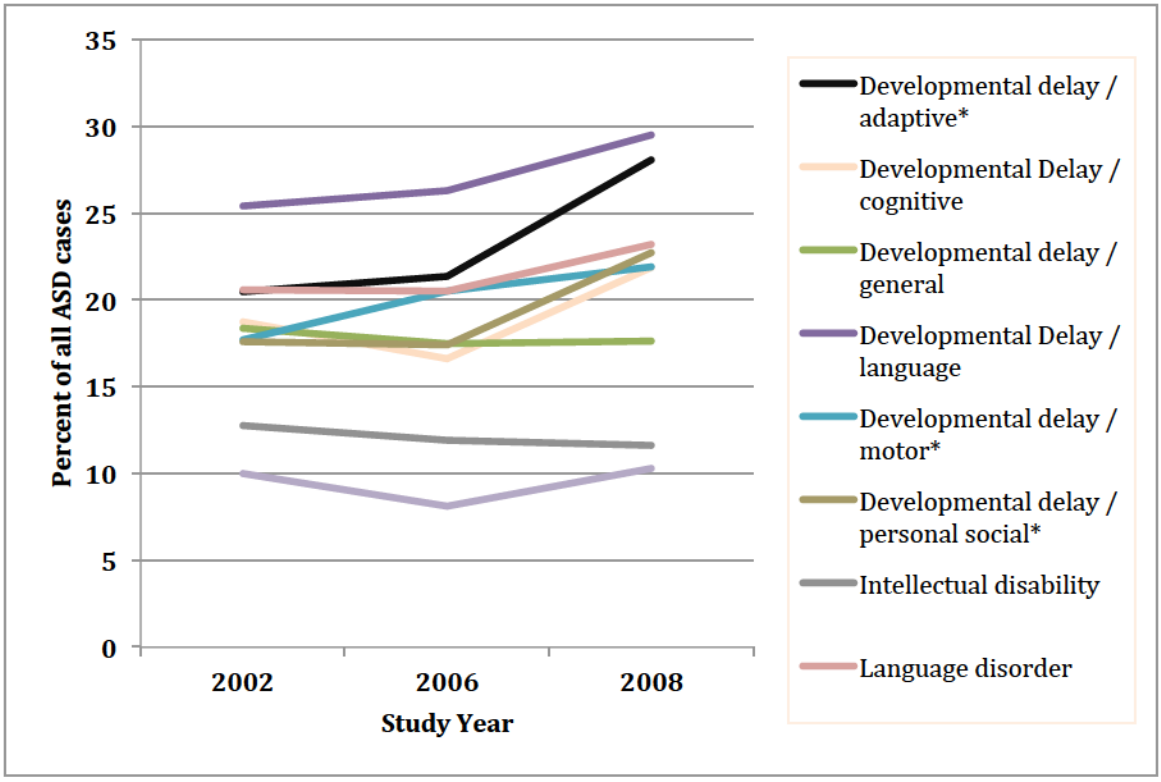


Figure 1.3 Trend in proportion of all ASD cases with a DACC in a given diagnostic category



* Indicates significance

Figure 1.4 Trends in proportion in all ASD cases with a given DACC



* Indicates significance, condition included if prevalence >5% for at least one surveillance year

Figure 1. 5 Trends in proportion of children with ASD and a categorized DACC, stratified by previous ASD diagnosis status or ID status

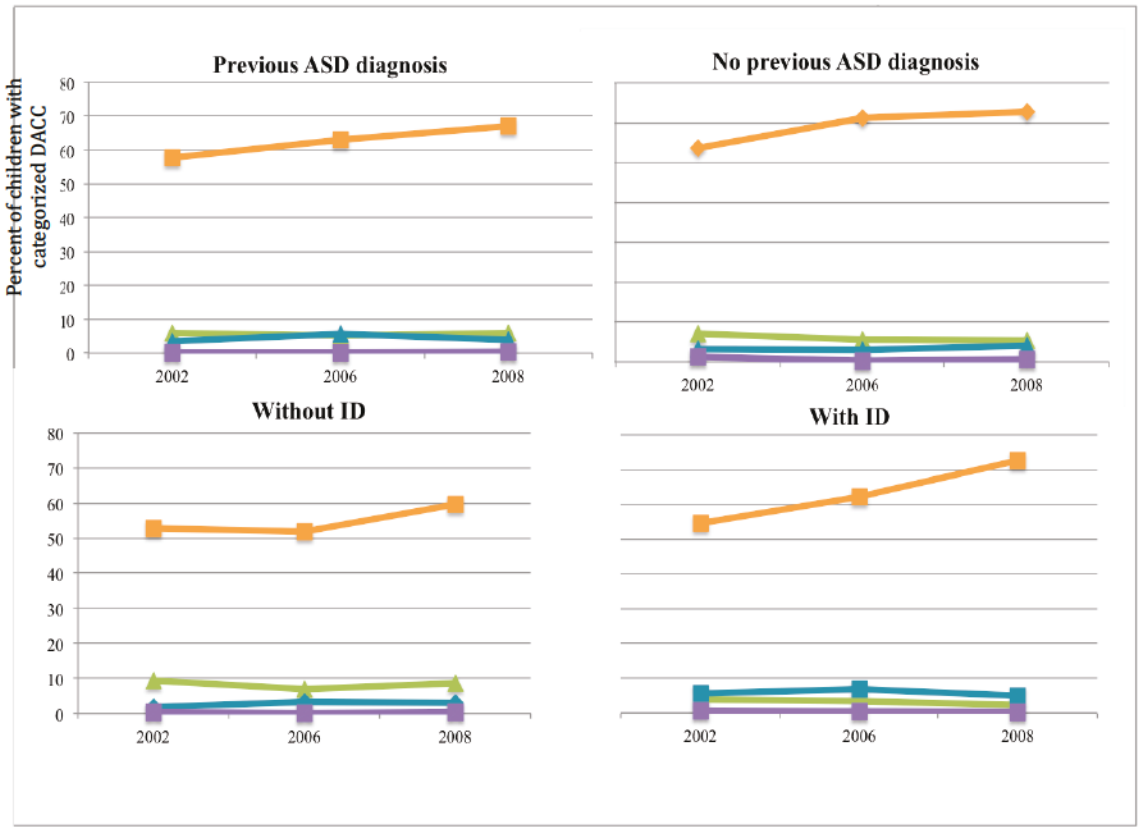
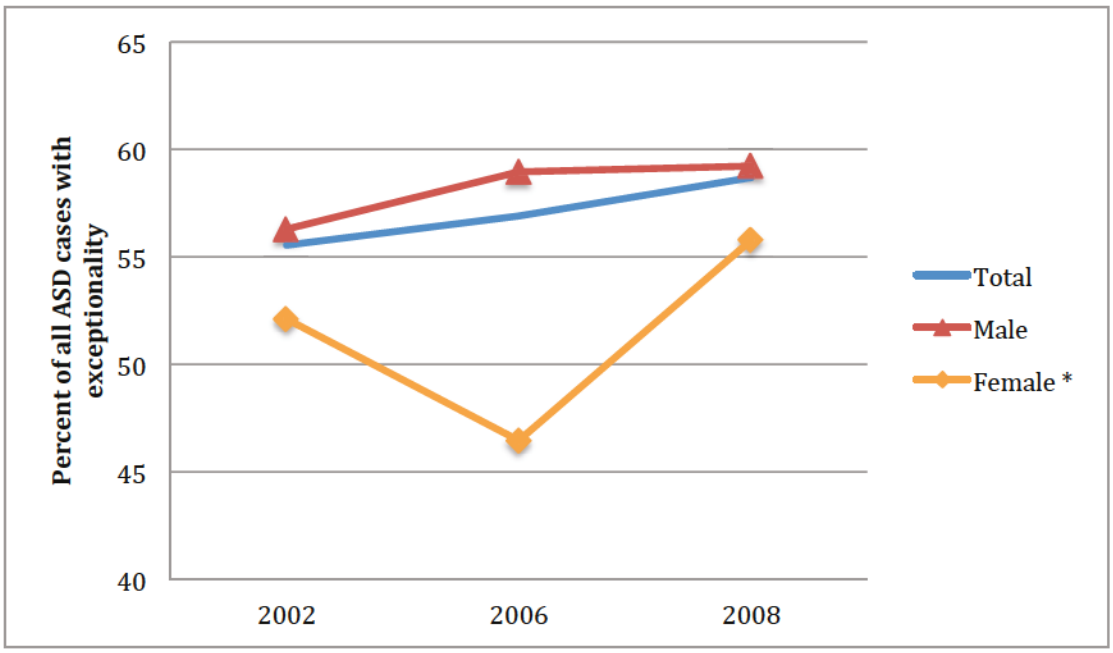


Table 2.7 Risk ratios and confidence intervals comparing special education exceptionalities in children with ASD in the ADDM Network

	Total		Male		Female		White, non-Hispanic		Black, non-Hispanic		Hispanic	
	2002 vs. 2006	2002 vs. 2008	2002 vs. 2006	2006 vs. 2008	2002 vs. 2006	2002 vs. 2008	2002 vs. 2006	2002 vs. 2008	2002 vs. 2006	2002 vs. 2008	2002 vs. 2006	2002 vs. 2008
Autism	1.02 (0.95-1.11)	1.06 (0.99-1.13)	1.048 (0.97-1.13)	1.05 (0.97-1.13)	0.89 (0.73-1.09)	1.07 (0.89-1.28)	1.02 (0.93-1.13)	1.03 (0.94-1.13)	1.00 (0.89-1.14)	1.05 (0.93-1.18)	1.11 (.82-1.51)	1.14 (.84-1.54)
Emotional Disturbance	0.62 (0.44-.089)	0.66 (0.47-.92)	0.59 (0.39-0.87)	0.63 (0.44-0.92)	0.82 (0.36-1.86)	0.81 (0.37-1.78)	0.69 (0.45-1.05)	0.62 0(0.41-0.95)	0.73 (0.32-1.66)	0.66 (0.31-1.44)	0.41 (0.11-1.61)	1.06 (0.35-3.21)
Specific Learning Disability	0.92 (0.69-1.22)	0.87 (0.66-1.15)	0.66 (0.70-1.32)	0.87 (0.64-1.18)	0.68 (0.36-1.44)	0.89 (0.46-1.74)	0.84 (0.56-1.26)	0.86 (0.59-1.27)	1.00 (0.54-1.88)	1.08 (.60-1.92)	1.05 (0.51-2.18)	0.71 (0.33-1.52)
Speech language Impairment	0.93 (0.71-1.23)	0.81 (0.62-1.06)	0.86 (0.63-1.16)	0.81 (.60-1.08)	1.47 0(.70-2.66)	0.77 (0.37-1.59)	0.80 (0.57-1.13)	0.75 (0.53-1.05)	1.18 (0.60-2.32)	0.80 (0.41-1.59)	0.88 (0.39-1.95)	1.15 (0.54-2.44)
Hearing / Visual Impairment	-	-	-	-	-	-	-	-	-	-	-	-
Orthopedic Impairment	0.63 (0.27-1.52)	1.19 (0.57-2.49)	0.63 (0.26-1.49)	0.96 (0.45-2.06)	-	-	0.39 (0.11-1.34)	1.44 (0.60-3.46)	0.73 (0.10-5.17)	0.52 (0.074-3.68)	-	-
Traumatic Brain Injury	-	0.52 (0.032-8.27)	-	.51 (.03-8.09)	-	-	-	.60 (.037-9.50)	-	-	-	-
Other Health Impairment	**1.40 (1.03-1.90)**	1.17 (0.86-1.59)	1.28 (0.91-1.78)	1.14 (0.82-1.58)	2.25 (0.99-5.12)	1.32 (0.56-3.15)	**1.59 (1.09-2.31)**	**1.50 (1.04-2.18)**	0.85 (0.40-1.82)	0.83 (0.41-1.67)	1.24 (0.41-3.73)	0.89 (0.29-2.75)
Multiple Disabilities	1.10 (0.59-2.07)	0.93 (0.50-1.74)	1.00 (.45-2.19)	1.11 (0.53-2.34)	1.37 (0.48-3.93)	0.58 (0.17-1.97)	1.00 (0.47-2.14)	0.87 (0.40-1.85)	0.73 (0.10-5.17)	1.83 (0.38-8.72)	1.24 (0.26-6.01)	0.35 (0.05-2.48)
Intellectual Disability	0.77 (0.61-0.96)	0.62 (0.49-0.78)	.76 (.58-1.00)	0.63 (0.48-0.83)	0.80 (0.51-1.23)	0.60 (0.38-0.94)	0.84 (0.58-1.22)	**.62 (0.42-0.92)**	0.73 (0.49-1.09)	**0.55 (0.37-.082)**	0.65 (0.40-1.05)	**0.59 (0.37-0.95)**
Developmental Delay	**6.60 (2.65-16.47)**	**10.67 (4.37-26.10)**	**6.56 (2.36-18.23)**	**10.89 (4.01-29.57)**	6.85 (0.88-52.97)	**9.84 (1.32-73.29)**	**7.58 (1.79-32.10)**	**11.61 (2.81-47.87)**	**5.62 (1.71-18.51)**	**6.78 (2.12-21.72)**	-	-

Figure 2.6 Trends in proportion of autism exceptionality given child has ADDM identified ASD and any special education exceptionality by sex



*indicates significance, significant difference between male and female

Figure 2.7 Trends in autism exceptionality given child has an ADDM identified ASD by race / ethnicity

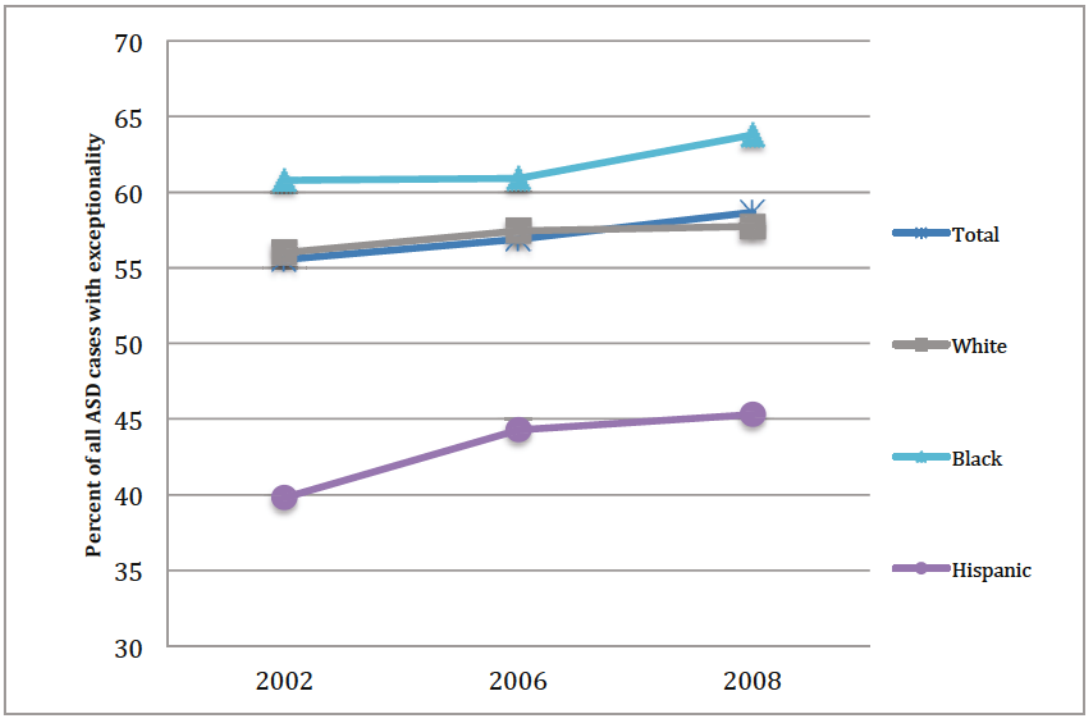
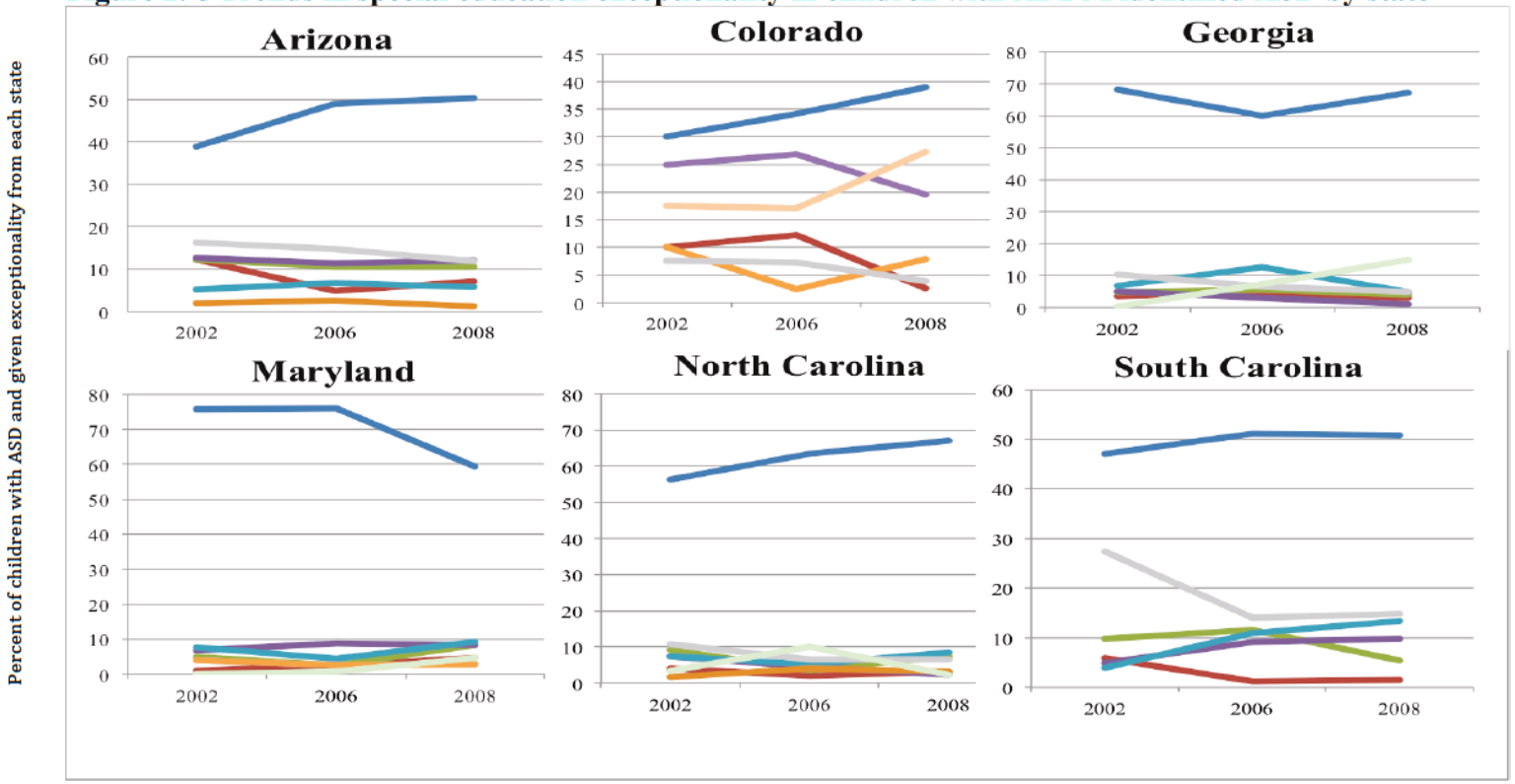


Figure 2. 8 Trends in special education exceptionality in children with ADDM identified ASD by state



References

Individuals with Disabilities Education Improvement Act 118, 446 Cong. Rec. (2004).

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Arlington, Va: American Psychiatric Publishing.

Amiet, C., Gourfinkel-An, I., Bouzamondo, A., Tordjman, S., Baulac, M., Lechat, P., . . . Cohen, D. (2008). Epilepsy in autism is associated with intellectual disability and gender: evidence from a meta-analysis. *Biological Psychiatry, 64*(7), 577-582. doi: 10.1016/j.biopsych.2008.04.030

Arunyanart, Wirongrong, Fenick, Ada, Ukritchon, Supak, Imjaijitt, Worarachanee, Northrup, Veronika, & Weitzman, Carol. (2012). Developmental and autism screening: A survey across six states. *Infants & Young Children, 25*(3), 175-187. doi: 10.1097/IYC.0b013e31825a5a42

Autism and Developmental Disabilities Monitoring Network. (2012). Prevalence of Autism Spectrum Disorders: Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. Morbidity and Mortality Weekly Report. Surveillance Summaries. Volume 61, Number 3.

Autism and Developmental Disabilities Monitoring Network. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *Morbidity and Mortality Weekly Report, 63*(2), 1-21.

Baird, G., Charman, T., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., . . . Simonoff, E. (2008). Regression, developmental trajectory and associated problems in disorders in the autism spectrum: the SNAP study. *Journal of Autism and Developmental Disorders, 38*(10), 1827-1836. doi: 10.1007/s10803-008-0571-9

Banach, R., Thompson, A., Szatmari, P., Goldberg, J., Tuff, L., Zwaigenbaum, L., & Mahoney, W. (2009). Brief Report: Relationship between non-verbal IQ and gender in autism. *Journal of Autism and Developmental Disorders, 39*(1), 188-193. doi: 10.1007/s10803-008-0612-4

Boyle, Coleen A., Boulet, Sheree, Schieve, Laura A., Cohen, Robin A., Blumberg, Stephen J., Yeargin-Allsopp, Marshalyn, . . . Kogan, Michael D. (2011). Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008. *Pediatrics, 127*(6), 1034-1042. doi: 10.1542/peds.2010-2989

Close, H. A., Lee, L. C., Kaufmann, C. N., & Zimmerman, A. W. (2012). Co-occurring conditions and change in diagnosis in autism spectrum disorders. *Pediatrics, 129*(2), e305-316. doi: 10.1542/peds.2011-1717

Coo, Helen, Ouellette-Kuntz, Hélène, Lloyd, Jennifer E. V., Kasmara, Liza, Holden, Jeanette J. A., & Lewis, M. E. Suzanne. (2008). Trends in autism prevalence: Diagnostic substitution revisited. *Journal of Autism and Developmental Disorders, 38*(6), 1036-1046. doi: 10.1007/s10803-007-0478-x

Council on Children With Disabilities Section on Developmental Behavioral Pediatrics Bright Futures Steering Committee Medical Home Initiatives for Children With Special Needs Project Advisory Committee. (2006). Identifying

Infants and Young Children With Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. *Pediatrics, 118*(1), 405-420. doi: 10.1542/peds.2006-1231

Croen, Lisa A., Grether, Judith K., Hoogstrate, Jenny, & Selvin, Steve. (2002). The changing prevalence of autism in California. *Journal of Autism and Developmental Disorders, 32*(3), 207-215. doi: 10.1023/A:1015453830880

Dosreis, S., Weiner, C. L., Johnson, L., & Newschaffer, C. J. (2006). Autism spectrum disorder screening and management practices among general pediatric providers. *Journal of Developmental and Behavioral Pediatrics, 27*(2 Suppl), S88-94. doi: 10.1097/00004703-200604002-00006

Fombonne, Eric. (2005). Epidemiology of autistic disorder and other pervasive developmental disorders. *Journal of Clinical Psychiatry, 66*(suppl 10), 3-8.

Gadow, K. D., Devincent, C. J., Pomeroy, J., & Azizian, A. (2005). Comparison of DSM-IV symptoms in elementary school-age children with PDD versus clinic and community samples. *Autism, 9*(4), 392-415. doi: 10.1177/1362361305056079

Grether, Judith K., Rosen, Nila J., Smith, Karen S., & Croen, Lisa A. (2009). Investigation of shifts in autism reporting in the California Department of Developmental Services. *Journal of Autism and Developmental Disorders, 39*(10), 1412-1419. doi: 10.1007/s10803-009-0754-z

King, Gary, & Zeng, Langche. (2001). Logistic Regression in Rare Events Data. *Political Analysis, 9*, 137-163.

King, Marissa, & Bearman, Peter. (2009). Diagnostic change and the increased prevalence of autism. *International Journal of Epidemiology, 38*(5), 1224-1234.

Lecavalier, Luc, Snow, Anne V., & Norris, Megan. (2011). Autism Spectrum Disorders and Intellectual Disability. In J.L Matson & P. Sturmey (Eds.), *International Handbook of Autism and Pervasive Developmental Disorders.* (pp. 37-51). New York: Springer.

Levy, S. E., Giarelli, E., Lee, L. C., Schieve, L. A., Kirby, R., Cunniff, C., . . . Rice, C. (2010). Autism Spectrum Disorder and Co-occurring Developmental, Psychiatric, and Medical Conditions Among Children in Multiple Populations of the United States. *Journal of Developmental and Behavioral Pediatrics, 31*(4), 267-275. doi: 10.1097/DBP.0b013e3181d5d03b

Maenner, Matthew J., & Durkin, Maureen S. (2010). Trends in the Prevalence of Autism on the Basis of Special Education Data. *Pediatrics, 126*(5), e1018-e1025. doi: 10.1542/peds.2010-1023

Mandell, David S., Novak, Maytali M., & Zubritsky, Cynthia D. (2005). Factors Associated With Age of Diagnosis Among Children With Autism Spectrum Disorders. *Pediatrics, 116*(6), 1480-1486. doi: 10.1542/peds.2005-0185

Matson, Johnny L., Beighley, Jennifer, & Turygin, Nicole. (2012). Autism diagnosis and screening: Factors to consider in differential diagnosis. *Research in Autism Spectrum Disorders, 6*(1), 19-24. doi: 10.1016/j.rasd.2011.08.003

Mattila, Marja-Leena, Hurtig, Tuula, Haapsamo, Helena, Jussila, Katja, Kuusikko-Gauffin, Sanna, Kielinen, Marko, . . . Moilanen, Irma. (2010). Comorbid psychiatric disorders associated with Asperger syndrome/high-functioning

autism: A community- and clinic-based study. *Journal of Autism and Developmental Disorders, 40*(9), 1080-1093. doi: 10.1007/s10803-010-0958-2

Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., . . . Windham, G. C. (2007). The epidemiology of autism spectrum disorders. *Annual Review of Public Health, 28*, 235-258. doi: 10.1146/annurev.publhealth.28.021406.144007

Pinborough-Zimmerman, Judith, Bakian, Amanda V., Fombonne, Eric, Bilder, Deborah, Taylor, Jocelyn, & McMahon, William M. (2012). Changes in the administrative prevalence of autism spectrum disorders: Contribution of special education and health from 2002–2008. *Journal of Autism and Developmental Disorders, 42*(4), 521-530. doi: 10.1007/s10803-011-1265-2

Radecki, L., Sand-Loud, N., O'Connor, K. G., Sharp, S., & Olson, L. M. (2011). Trends in the use of standardized tools for developmental screening in early childhood: 2002-2009. *Pediatrics, 128*(1), 14-19. doi: 10.1542/peds.2010-2180

Rosenberg, Rebecca E., Daniels, Amy M., Law, J. Kiely, Law, Paul A., & Kaufmann, Walter E. (2009). Trends in autism spectrum disorder diagnoses: 1994-2007. *Journal of Autism and Developmental Disorders, 39*(8), 1099-1111. doi: 10.1007/s10803-009-0723-6

Schendel, Diana E., Autry, Andrew, Wines, Roberta, & Moore, Cynthia. (2009). The co-occurrence of autism and birth defects Prevalence and risk in a population-based cohort. *Developmental Medicine and Child Neurology, 10*(51), 779-786. doi: 10.1111/j.1469-8749.2009.03310.x

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 47*(8), 921-929. doi: 10.1097/CHI.0b013e318179964f

Snyder, T.D, & Dillow, S.A. (2012). Digest of Education Statistics, 2011 (NCES- 2012-001). National Center for Education Statistics, Institute of Education Sciences, U.S Department of Education: Washington, DC.

Wiggins, Lisa D, Piazza, Vivian, & Robins, Diana L. (2014). Comparison of a broad-based screen versus disorder-specific screen in detecting young children with an autism spectrum disorder. *Autism, 18*(2), 76-84. doi: 10.1177/1362361312466962

Curriculum Vitae

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PROFILE

Master of Science in epidemiology student studying general epidemiology and epidemiological methods with a strong focus on child epidemiology, specifically autism spectrum disorder and developmental disabilities. Published researcher with experience in literature review, data management, data analysis, and manuscript writing. Community development experience as well as practice in working with children and young adults with developmental and physical disabilities. Computer skills include STATA, SAS, Microsoft Office products, ArcGIS, Endnote, R, SQL, and SPSS

EDUCATION

Master of Science in Epidemiology (ScM) Expected May 2014
Johns Hopkins Bloomberg School of Public Health (JHSPH), Baltimore, MD
Concentration (track): General Epidemiology and Methodology
Relevant Coursework (to be completed by May 2014): 4 terms of Epidemiologic Methods, 4 terms of Biostatistics, Introduction to Clinical Trials, Prenatal and Infant Growth and Development, Psychiatric Epidemiology, Research Ethics, Public Health Perspectives, Current Topics in Epidemiology, Introduction to Behavioral and Psychiatric Genetics, Issues in Survey Research, Introduction to SAS, STATA Programming, Methodological Challenges in Epidemiological Research, Statistics for Psychosocial Research, Genetic Epidemiology, Introduction to Database Management, Social Epidemiology, Introduction to Persuasive Communication
Current GPA: 3.75
Honors: Charlotte Ferencz Fellowship in Maternal and Child Health, Wendy Klag Autism Center Student Travel Award

Bachelor of Science in Public Health and Environmental Science May 2012
Rutgers University, New Brunswick, NJ
Honors: James Carr Scholar, Edward J Bloustein Scholar (4 year merit scholarships)

RESEARCH EXPERIENCE

Graduate Research Assistant October 2012-present
Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

- Managing and analyzing data relevant to autism spectrum disorder (ASD)
- Writing literature reviews, managing and analyzing data, leading workgroups, and primary author of manuscripts for thesis projects and journal articles

- Currently assessing temporal changes in special education classification, co-occurring conditions, and intellectual disabilities in children with ASD

Intern
Maryland Center for Developmental Disabilities January 2014-present
- Provide assistance in research projects related to autism spectrum disorder and other developmental disabilities
- Develop and implement a data collaborative to effectively and efficiently share data between organizations that collect data on developmental disabilities in Maryland

Subcontractor
Innovative Science, Morristown, NJ July 2013-October 2013
- Researching epidemiology of hospital associated infections and products best used to combat these infections
- Evaluating data and scientific material for sterilization products
- Creating product brochure to highlight scientific and economic merits hospital cleaning product
- Designing experimental tests and epidemiological studies to assess sterilization products for hospitals

Research Assistant January-July 2012
National Institute for Early Education Research, New Brunswick, NJ
- Assisted in data entry and data cleaning for early education research projects
- Designed and developed databases for organizing data from pre-school research projects
- Archived journal articles and documents for computer based library

Research Intern June-August 2011
New Jersey Safe Schools, New Brunswick, NJ
- Conducted research examining injuries amongst special needs students using personal protective equipment in school run occupational work programs
- Analyzed data which was used in a journal article pending peer review
- Led vocational education safety workshops

TEACHING EXPERIENCE

Lead Teaching Assistant August 2013-present
Johns Hopkins Bloomberg School of Public Health, Baltimore MD
- Principles of Epidemiology

- Oversee all labs and office hours, lead instructors meetings, grade assignments, answer student questions, and organize class materials

Teaching Assistant June 2013-August 2013
Johns Hopkins Bloomberg School of Public Health, Baltimore MD

- Principles of Epidemiology Summer Institute
- Principles of Epidemiology
- Instructed labs, answered student questions, held office hours, led class discussions, and graded assignments and tests

Substitute Teaching Assistant March-August 2011
Eden Autism Services, Princeton, NJ

- Worked one on one with children with autism in a school setting using Applied Behavioral Analysis
- Collected and graphed behavioral and educational data
- Developed children's verbal, social, and behavioral skills

COMMUNITY INVOLVEMENT

Volunteer Resource Manager 2008-20012
Community Development Corp, New Brunswick, NJ

- Delivered medical equipment and baby supplies to low income residents of Middlesex County, NJ
- Organized and managed supply warehouse

Volunteer Coach November 2012- present
Special Olympics Baltimore County

- Teaching basketball and track and field skills to athletes of varying ability
- Organizing practices and managing athletes with special needs

Financial Committee Member August 2013 – present
Project Bridge

- Find and write grants plus manage finances for an organization devoted to enhancing scientific literacy in the Baltimore community

Walk Committee Member June 2013-present
Autism Speaks

- Help plan and organize major charity walk that raised over $250,000
- Find sponsors and donations for the walk
- Represented Autism Speaks at community events

PROFFESSIONAL MEMBERSHIPS

2010-present	American Public Health Association
2012- present	JHSPH Epidemiology Student Organization
2013- present	Organization for the Study of Sex Differences
2013-present	International Society of Autism Researchers

PRESENTATIONS

Rubenstein E., Rice C., Van Naarden, K., Schieve, L., Durkin, M., Christenson, D., Bakian, A., Wiggins, L., Daniels, J., Lee, L.C. Trends in ASD DACCs in the ADDM Network. Poster to be presented at the International Meeting for Autism Researches, May 2014.

Rubenstein, E., Wiggins, L., Lee, LC., A review of the differences in symptom profiles and co-occurring conditions between males and females with Autism Spectrum Disorders. Poster presented at the Maryland Public Health Association Annual Meeting, September 2013.

Rubenstein, E., Wiggins, L., Lee, LC., A review of the differences in symptom profiles and co-occurring conditions between males and females with Autism Spectrum Disorders. Poster presented at the 7th Annual Organization for the Study of Sex Differences, April 2013.

Rubenstein, E., Shendell, D,G., et. al. Personal Protective Equipment Use By Individualized Education Plans (IEP) Students in Vocational, Career and Technical Education (CTE) Programs. Poster presented at the 140th Annual APHA Meeting and Exposition, October 2012.

PUBLICATIONS

Rubenstein E., Shendell D., Eggert B., Marcella S.(2014). Personal Protective Equipment Use Among Students With Special Health Care Needs Reporting Injuries in School-Sponsored Vocational, Career, and Technical Education Programs in New Jersey. *AAOHN J.* 62(1) 12-18. doi: 10.3928/21650799-20131220-03

WORK SUBMITTED FOR PUBLICATION

Rubenstein, E., Wiggins, L., Lee, LC. (2013) A review of the differences in symptom profiles and co-occurring conditions between males and females with Autism Spectrum Disorders. Research in Autism Spectrum Disorder